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THE DEVELOPMENT OF A NEW MODEL FOR ASSESSING AFRICAN-
AMERICAN SPIRITUALITY IN PALLIATIVE CARE

A Dissertation

Submitted to the McNulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

John C. Welch

April 2016

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John C. Welch

2015

THE DEVELOPMENT OF A NEW MODEL FOR ASSESSING AFRICAN-
AMERICAN SPIRITUALITY IN PALLIATIVE CARE

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Approved December 10, 2015

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ABSTRACT

THE DEVELOPMENT OF A NEW MODEL FOR ASSESSING AFRICAN- AMERICAN SPIRITUALITY IN PALLIATIVE CARE

By

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April 2016

Dissertation supervised by Henk ten Have, MD, PhD

Research has shown that African-Americans are least likely to receive adequate palliative interventions leading to concerns about the quality of health care in general and palliative care in particular for this population. Acknowledging patient preferences are essential in administering quality health care especially when a patient's condition is terminal. But when African-Americans are least likely to complete living wills or durable power of attorneys for health care and more likely to continue to request life sustaining treatments when near death, conflicts between patients and medical professionals can result.

Recognizing patient spirituality and addressing their spiritual needs can help the patient, family or surrogate decision-maker come to terms with, if not make sense of, their life-threatening illness and eventual mortality. This may be especially salient for African-Americans because of their history of victimization of racial discrimination and ensuing overwhelming challenges with sometimes tragic consequences. Models and approaches used to assess the spirituality of African-American patients must be culturally

appropriate and performed by professionals with interpersonal communications skills and an awareness of how their implicit bias can impede the integrity of the clinician-patient interaction.

DEDICATION

I dedicate this body of work in memoriam to my grandmother Bernice who believed in me and made the first investment in my education from the beginnings of my school days through college and to my father John and to my mother Della in memoriam for giving me life. Lastly, and most importantly I dedicate this dissertation to my wife DeNeice who supported me every step of the way and prayed me through to the end of this journey. To my four children, Aja, Jordan, John Christopher, and Ian, my grandchildren Ayauna, Genesis, and Aiden, the one in utero who is fully known by God, I pray that I have inspired you to reach as far as you can and believe you can attain the ultimate in whatever you pursue with God's help.

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Chapter 1. Introduction

In the scholarly literature it is argued that spirituality helps the patient address the existential questions of life, often invoked at the time of terminal diagnoses or when death is imminent. It is further suggested that identifying with patients' spirituality and addressing their spiritual needs can help the patients and their decision-makers come to terms with, if not make sense of, terminal illness and even eventual mortality. This may be especially salient for African-Americans because of their history facing overwhelming challenges and at times tragic circumstances in life. This dissertation will explore the spirituality of African-Americans and how it can be leveraged to enhance palliative care and potentially decrease health care disparities for patients with life-threatening illness. Since spirituality is a core component of palliative care, deficient attention to patient spirituality creates an unethical dilemma because it impedes human flourishing even in the midst of suffering. Moreover, in this dissertation it will be argued how developing a new framework by expanding the definition of spirituality, with the dimension of personhood and not strictly activity based spirituality, e.g. prayer, meditation, church attendance, etc., often employed in past research on spirituality and medicine, can fortify physician understanding of patient wishes, thereby implementing timely treatment interventions concordant with patient values thereby promoting the human dignity of the dying patient.

Before examining the importance of spirituality in palliative care, Chapter One will first begin expounding on the historical development of palliative care, the definition of palliative care, the ethics of palliative care, the role of spirituality and palliative care, and African-American perspectives on medical ethics. Beginning in the oncology wards

at St. Christopher's Hospice in the UK under the direction of Cicely Saunders and primarily administered by nurses, palliative care and hospice were parallel developments. Later developments saw the creation of multidisciplinary support teams in hospitals in the 1970s, expanding from hospice and nursing homes; however, this development of teams was slower in the United States compared to the UK. How palliative care is viewed within healthcare varies from one system to the next both locally and internationally. It is still viewed by some as end of life care and not care provided throughout the life of chronic illness starting with diagnosis. By providing clarity in definition and applying this concept consistently the efficacy of this care could be enhanced for African-American patients. This discourse on clarity and efficacy invites a discussion on the ethics of palliative care. The Hospice Palliative Care Association code of Ethics suggests patients' right to self-determination and the respect for human dignity are fundamentally foundational in patient care. In the midst of the suffering that can accompany diseases, like cancer, a patient still wants to have his or her wishes respected and human worth recognized. Truth telling is also significant in facilitating informed consent and patient autonomy; however, physicians should be sensitive to patient and family culture and values as they may conflict with physician treatment preferences. Another important ethical issue for palliative care is access. From 2000 to 2011 the number of hospitals in the U.S. with palliative care programs increased; however, implementation across the 50 states is inconsistent. Despite the overall improvement in the number of hospitals with palliative care programs, the fact that there are some patients who are potentially denied this type of care in certain parts of the country creates an ethical dilemma. What seems to be even more problematic is that if the general public in some of the states where

palliative care is less saturated are not benefiting, for African-Americans this inaccessibility to care can be even more acute given the fact, generally speaking, African-Americans are more likely to receive substandard care for a variety of reasons including but not limited to racism and cultural incompetence.

There exists extensive quantitative and qualitative research that looks at the interweaving of spirituality and medicine but much of this research looks at human activity as a link to outcome based medicine, which often permeates into the sphere of religion and abandoning the authenticity of spirituality. This may also be the case in medical school curricula where courses on spirituality focus more on cross-cultural beliefs and religious practices. In general, scholars believe that the use of spirituality in addressing the existential questions of life are often invoked at the time of diagnoses of a life-threatening illness diagnoses or when death is immanent. This may be especially salient for African-Americans who have historically faced tragic circumstances in life. African-Americans though a unique population, are often grouped with other ethnic minority groups in socio-political, medical, and sociological discourses.

Scholars from a variety of disciplines have long studied health and health care disparities between whites and African-Americans. Concurrent with the disproportionately high morbidity and mortality rates of African-Americans there is also a low utilization of advance directives, palliative interventions and hospice care, leading to concerns about the quality of end of life care for this population. Literature suggests that biases, stereotyping, cultural incompetence, and the lack of training on the part of medical professionals contribute to this dilemma. Concomitantly, social, cultural and behavior determinants and the mistrust of the health care system by African-Americans

are also reasons behind the high rate of health and health care disparities between whites and African-Americans. While it would be too expansive for this work to consider how all of the aforementioned determinants undermine quality health care for African-Americans, the aim of this dissertation is to focus on those that pertain to the care offered by medical professionals.

Similar to, but distinct from other ethnic groups, African-Americans have an exclusive etiology; their self-identification is based on the unfortunate history of abuse and exploitation at the hands of Whites in this country. To that end, spirituality has been the bedrock for existential challenges and the source of their perseverance, developed as a response to this exploitation and oppression. To that end Chapter Three explores the historical development of race and racism, the continued mistreatment of African Americans through the course of American history from slavery to the 21st century, its justification and legitimizing through legislative frameworks, and the pathways within the confines of medicine as well. Before attempting to outline how the health and wellbeing of African-Americans were diminished by discriminatory practices based on race it is important to begin with an analysis of the origins of the concept of race and its pejorative applications. To that end, it is important to, in as brief yet succinct a manner as possible, trace the origins of the term “race” and the subsequent influences and eventual mistreatment of African-Americans. In doing so, the ways in which “race” has been engrained throughout the various domains in the U.S., especially in healthcare, will be explored.

Traveling back in time gives a glimpse of what gave rise to the pejorative and at times vile depictions of those who would later become African-Americans. Galen, a

Roman physician in or around the time of AD 160 described African men as having oversized genitalia with inferior intellect. Philo, a respected Hellenistic-Jewish philosopher from the 1st century put a face on evil by associating it with the Ethiopians despite no explicit or implicit support of biblical evidence. Others did likewise such as 2nd century theologians Origen and Irenaeus, both of whom used poetic license to take scriptures that refer to darkness and make reference to Ethiopians, thereby expanding negative connotations towards Ethiopians or Africans.

The degenerative use of the term race seemed to gain influence through the works of Georges-Louis Leclerc, Comte de Buffon, the 18th century French naturalist. He was the first to use the term race to designate previously identified human subgroups – Europeans, Asians, Americans and Africans. Despite inexact science and inconsistent use of the term, Leclerc proposed that race was rooted in climate and geographic variations. But this proposition on the construct of race was not limited to the scholarship of naturalists and anthropologists. The schools of philosophy also offered their share of opinions. David Hume, the noted 18th century philosopher purported that all human species or races were inferior to the White race and that nations of complexions other than white were uncivilized. Immanuel Kant, a contemporary of Hume, and the one credited in the world of philosophical ethics with the categorical imperative, foundational in deontological ethics, offered a similar pejorative narrative of the Negroes in Africa asserting that Negroes of Africa were trifling by nature. Kant's views were also sharp toward African religion when he described African worship as idolatrous and trifling making reference to their use of bird feathers, conch shells, cow horns and other objects.

It is this type of thinking that gave rise to the misunderstanding that missionaries converted African slaves to Christianity.

What was just described is how the soil was tilled before planting the seeds of slavery in America. The whole notion of using Africans as slaves was started by the Portuguese and Spaniards during religious wars against Moors. The Portuguese in their travels down the coast of Africa would transport Africans back to Portugal. Thousands were taken before the year 1500 and used as slaves. After the year 1500 Portugal and Spain had developed a lucrative system of delivering slaves to the Americas. Africans in the minds of the explorers, English and non-English, were savages. When the English were made aware Spain and Portugal's slave trade operations from Africa to the West Indies, these operations did not seem heathenness to them. In fact, what would become a token of unpleasant irony, an 18th century Christian English sailor by the name of John Newton would be instrumental in carrying African slaves from Africa to America on the ship he captained. This same John Newton was the writer of some of the more prominent hymns used in the Christian church – "Amazing Grace." It was not antithetical to have a strong faith in God on the top deck of a ship while the cargo he carried below were Africans ready to be sold into slavery. This twisted form of religious piety would later become pervasive in the English colonies and eventually the United States of America. Those Africans who were captured on their soil traveled upwards of 500 miles on foot. While on the ships during the transatlantic trip known as the Middle Passage, the slaves, men and women, were compressed into the lower compartment of the ship, body against body so much so that the slaves were not even able to turn around. The travel on these

ships would take anywhere from approximately 6-10 weeks as some slaves would either suffocate to death or go mad in the process.

In the West Indies the overcrowding of Europeans gave way to influx of African slaves as free labor to work the sugar plantations as the Europeans migrated to the English colonies and to the larger island of Jamaica. The enslavement of Africans in the West Indies was influential in the New England area even though there were no plantations in New England and no staple crops to farm; thusly, there was no economic justification. It is believed that those who brought the Africans from the island colonies to the New England area and sold them, did so with the notion of keeping the slaves under perpetual servitude rather than providing any hope of liberation and shifting their status to indentured servitude. Unlike New England, things were developmentally different in the Maryland and Virginia areas during this time because in these two colonies there was the need for cheap labor to work the tobacco farms. In the West Indies it was sugar. In early 17th century Virginia, much of the work in the tobacco fields was performed by English indentured servants. It wasn't until later in the century that colonialists began buying Africans from the West Indies and after 1680 they were purchased directly from Africa. Those Englishmen who worked the fields did so as indentured servants, not slaves. Despite this hard fieldwork, they enjoyed the luxury of knowing that after a term they would be free. The powerlessness of slaves during this time left them extremely vulnerable to the whims of not only plantation owners but also physicians. The working conditions for many slaves were brutal. With the high rate of immigration of Europeans into the country during this time, and the forced importation of slaves from Africa and the West Indies, diseases were transported across the Atlantic and Caribbean with the same

ease as the travelers' luggage. Medicines and care was not well advanced and public health was an issue in Europe. Because development was even slower in this country public health conditions were worse. The vaccines and other advances in Europe were slow to make their way to America. Diseases from Europe and Africa would converge in the tropical climate of the South where the pathogens found a fertile environment. 90 percent of the Black population in this country lived in the South at this time.

By the time the 18th century came around, chattel slavery was well underway in every English colony. What is important to also recognize is that by this time, particularly by the first quarter of the century, one-third of the population in English colonies was Negro and by the middle of the century some Whites lived in neighborhoods where Negroes outnumbered them. In the area of political representation this created two problems. The first was this surge in population created an imbalance in representation in national government. The second problem, which contributed to the first, was that English colonist were confronted with actually how to account for the slaves that they owned. Governmental representation would be a problem that would create the seed of contention between the North and the South en route to and after the Civil War. While the slaves were already living in confinement, free Negroes in the north still faced challenges of their own, especially due to the famous decision rendered by the Supreme Court in the *Dred Scott v Sanford* case in 1857. The Supreme Court decision basically upheld the notion that based on the Constitution the "Negro" was not a whole person, (three-fifths of a person) and therefore not a citizen of the United States. This decision was as much a move at devaluing African-Americans, as it was to balance political representation between states with slaves and states without.

Medicine in the American South was experimental and the experimental subjects were often the expendable slaves. Informed consent was not required in those days. Yet, experimentation and treatment were conducted on slaves by the consent of the slave owners since slaves were no more than property anyway. These experiments were hazardous in nature and would never have been practiced on Whites but were performed on slaves because they only counted as three-fifths of a person, But perhaps no physician was more sinister and ruthless in practice than Dr. James Marion Sims. For one, he was considered the father of modern gynecology. His experiments were primarily on children in tetany and women with vesicovaginal fistula although he did purchase about seventeen male slaves to experiment on or to work in his clinic. Sims theorized that the tetany of Negro children was due to the displacement of skull bones during childbirth as opposed to vitamin D, calcium and magnesium deficiency due to malnutrition. So his remedy was to crack open the skull of a child and with a cobbler's tool and reposition the skull. Sims later acquired eleven women slaves that were diagnosed with vesicovaginal fistula and experimented on them over a four-year period, without anesthesia.

The period after the Civil War, known as Reconstruction, did not offer much in liberation for slaves once emancipated. This period is considered the most transformative period regarding government configuration and societal interactions as the nation wrestled with, not only emancipated slaves, but also federalism, citizenship, equality and rights. The War and what was to follow opened the door for significant changes regarding civil rights in the Constitution. It is interesting to note that the framers of the Constitution were deliberate in the choice of wording. The Constitution was constructed with the intention of configuring an inherent weakness of the Federal government in

regards to its relation to states rights and private property. The period from 1866 to 1875 was a crucial time period. It was a period of hopeful liberation and victory for former slaves, Negroes in “free” states and abolitionists by way of legislative actions. Reeling from the inertia of the war, more and more Negroes began to enter politics and realized other advances in civic and political life as they sought for the recognition of equal rights. Also During this period there were three amendments made to the Constitution, the Thirteenth, Fourteenth and Fifteenth Amendments. The Thirteenth Amendment abolished any forms of slavery or involuntary servitude except for in cases where warranted as punishment for a crime. Also attached to this amendment was a civil rights bill, passed in 1866, that declared all persons born in the United States were citizens of the United States, an act that overturned the *Dred Scott* ruling of the previous Judicial Court. It was expected that with the passage of this amendment, former slaves were not only freed but that they would be afforded the minimal rights as well as protection for them and their White supporters by the Federal government, through Congressional action, against such abuses as kidnapping, imprisonment and murder from White oppositionists in the South. But that was not to be the case for despite the amendment, these atrocities continued. These battles for state sovereignty and federal powers continued for decades.

Perhaps the most brutal of all the exploits in the South during this time was the lynchings. From 1863 until the Great Depression, there were over 3,000 African-Americans lynched in the South. African-Americans were a perceived economic and political threat to Whites who wanted to maintain their social superiority. Whenever cotton production was low, lynchings increased; whenever cotton production was high, lynchings decreased. When production was down Whites were substituted as laborers and

lynching was the intimidation used to keep African-Americans at bay. The last recorded lynching took place in 1964 and by then they had taken place in forty-nine states as far north as Maine and Vermont.

A few key Supreme Court decisions began to chisel away pieces of the Jim Crow structure. In 1937 they issued a unanimous judgment stating that it was unconstitutional to deny Blacks access to such railroad passenger cars. A second was in 1946 where the Supreme Court ruled that in reference to interstate travel, Virginia's law of segregating transportation was unconstitutional. Lastly, the Supreme Court again ruled unanimously against segregated dining car facilities in *Henderson v. United States* in 1950. Despite these Supreme Court victories, African-Americans were still disenfranchised and exploited. The Tuskegee Syphilis study is perhaps one of the most well known examples of the inhumane treatment of African-Americans at the hands of and for the advancement of medical science. Beginning in 1932 and lasting through 1972, the government-funded experiment involved a trial of four hundred African-American men, sharecroppers in Macon County, Alabama, used to test the effects of untreated syphilis. This program sponsored by the U.S. Public Health Service deceived infected men into thinking they were going to receive free medical care only to be used as guinea pigs in the study. These men were profiled as intellectually inferior, degenerate, impetuous, and sexually aggressive. There were similar experiments taking place overseas. Even before informed consent became law in this country and before the Nuremberg code of 1947, there was evidence of its requirement overseas when in 1898 Dr. Albert Neisser, of the University of Breslau in Prussia, used serum therapy on syphilis patients, mostly prostitutes. Despite the support of other academic physicians, Neisser was fined by the Royal Disciplinary

Court with the court also ruling that he should have sought patient consent despite the low risk of patient harm.

For over forty years, beginning in 1929, the state of North Carolina administered the largest sterilization program in the country, long after other states had rolled back their efforts in the light of the sterilization movements in Nazi Germany. More than thirty other states had eugenics sterilization programs but none to the extent of North Carolina. Their premise was population control, namely reducing the population of mentally and physically ill and curbing social malignancy through sterilization. The victims were primarily poor and predominantly African-American. The North Carolina legislature passed a law in 1929 and rewrote it in 1933 authorizing sterilization on people that were feeble-minded, epileptic and had other illnesses. North Carolina was also the only state where even social workers had the authority to recommend sterilization. This was uncovered through an investigation by the Winston-Salem Journal only to discover their complicity in the movement during that moment in history as they served as advertisers. It was discovered that the program managed to persist in North Carolina due to the self-interest and financial support of James G. Hanes of the Hanes Hosiery undergarment enterprise and Dr. Clarence Gamble of Boston, benefactor of the Proctor & Gamble chest. They argued that welfare mothers as well as the mentally ill were a burden to taxpayers. What is not often shared is when Germany launched its sterilization program in 1934 there were already seventeen states in this country with approved sterilization programs. One significant point to address on the issue of eugenics and sterilization, which still has an echoing effect today, is the work of Margaret Sanger, the pioneer behind women's birth control and the founder of what is known as Planned Parenthood,

one of the largest charitable organizations in the country today. Sanger started the Negro Project designed to assist African-American women unable to access health services in the city. Through her family planning centers eugenics principles were used as a means of reducing the African-American population. When abortion was still illegal, it was Margaret Sanger who supported the development of the birth control pill and intentionally made it available through Planned Parenthood free to African-American women in the urban areas. Consistent with this are the reports of countless African-American women who underwent involuntary hysterectomies. In the South it became so common for an African-American woman to have an involuntary hysterectomy during surgery for other issues that it became tagged as a Mississippi Appendectomy. But this practice was not limited to the South.

After the assassination of President Kennedy and the assumption of the presidency by Lyndon B. Johnson the Civil Rights Act of 1964 became law. Although this was an omnibus bill with interests fanning a number of areas, like its 1875 predecessor civil rights bill one of its focuses was on public accommodations. As could have been expected this act was put to the legal test by southerners. One such case was *Heart of Atlanta Motel v. United States* in 1964. The Supreme Court later unanimously upheld the Civil Rights Act. Hoping this federal victory would bring respite for mistreated African-Americans, the hope was short lived. Medical mistreatment continued During the 1970s African-American women who were pregnant and wanted abortions were forced to compromise for sterilization with some physicians. It was also estimated that in Alabama between 100,000 to 150,000 poor women were sterilized every year. In hospitals in New York and Boston, these involuntary hysterectomies were still performed

on African-American and Puerto Rican women to give medical residents practice. However, in 1972 Boston City Hospital medical students raised a protest against this practice. In consideration of all of the struggles of African-Americans across the four hundred plus years of living, working and existing as residents in this country, one cannot ignore the spiritual energy that has driven the will of this people to survive and overcome.

For African-Americans, this history of struggle and the evidence of endurance have long been attributed to the reliance on their faith. Therefore, understanding the development of their distinctive spirituality, its influence within healthcare and how the nuance of African-American spirituality and culture uniquely locates within patient care is important. In Chapter Four the definition of spirituality and its distinction from religion will be explored. More importantly to locate the significant contribution African-American spirituality offers in the context of palliative care an understanding of this spiritual development is important. It parallels the historical pain of African-Americans and their African ancestors because this spirituality fed their endurance as it carried them through the Middle Passage onto plantations of the South and North, and was fed by their endurance in the establishment of the Black Church. Some of the characteristics of African traditional religion are that it maintains the belief in a Supreme Being, active in the daily lives of its adherents, with powers more supreme than any other. Although similar in some respects to Christianity, this Supreme Being was different in that the Supreme Being was approachable through various intermediaries. In African traditional religion there is also no separation of the sacred and secular. This holistic worldview is what crystallized the sacredness of humanity because being human meant being spiritual. What was common among the slaves was the foundation of their African traditional

religion, which was highly ritualistic. It was common practice to believe in the supernatural powers of their ancestors and the role of these ancestors as protectors in daily life. While the expansion of Christianity into the continent of Africa traces back to the Middle Ages it is important to note the similarities between the Catholic faith and African traditional religion. In particular, African ancestry worship was not dissimilar to the Catholic tradition of praying to patron saints, believing that the ancestors also had the power of intercession. Christianity alone was not capable of providing the slaves all that they needed to develop the fortitude to resist and persist through the atrocities of slavery; therefore, slave Christianity was enriched by the components of their African traditional religion. Accepting Christianity was very difficult for some slaves because they recognized the obvious double standard while others accepted it in hopes that it would eventually lead to their freedom.

Slave religion, or African-American spirituality, during this time, was about mental and physical survival and so the slaves would interpret their situation and communicate hope to one another in the singing of the Negro spirituals which on the one hand seemed to be litanies of gloom and sorrow but on the other hand were the means of their nourishment. The spirituals were an example of a communal product. They were formulated from familiar African tunes blended with scriptural interpretation and improvisation. The slaves would often sing and dance late into the night or all night some times and in order to keep from being heard by their masters they would take the wash pots or the iron cooking pots and turn them upside down on the ground in order to keep from being heard on the outside. It was through the spirituals that slaves concentrated on their relationship with God in code language undecipherable to their masters due to the

ethereal and otherworldly connotations. A certain theology was emanating from these songs and these songs were creating a particular theology that added to the complexity of African-American spirituality. This theology was one of liberation, perseverance, and trust in a God that is powerful, loving, compassionate, just and righteous. It is important to recognize the location of trust for surely it was obvious whom the slaves did not trust. This theology became the foundation for “Black religion” and Black theology, a theology of suffering within a religious framework. And therefore how African-Americans were able to find hope in the mysteries of their spirituality amid the mistrust toward white controlled institutions, including healthcare, is the essence of this fourth chapter.

Illness is a spiritual matter. This is supported within African-American spirituality as it was also supported in African traditional religions. Spirituality and medicine have been in relationship for hundreds of years and originally symbiotically as clerics attended to the body and spirit. Even earlier hospitals were created through the work of religious societies. Over the years there has been increasing interest in the effect of spirituality and religion in health outcomes especially in the late 20th century. In pondering the substantive relationship between spirituality and medicine scholars suggest that as physicians are committed to the art of healing, which in essence means to make whole, then it is important for them to understand how disease affects the patient as a spiritual being with ontological questions. There are some who find the separation of medicine and spirituality mutually beneficial in respect to the pluralism in the United States and because the term spirituality carries an inherent bias favoring the supernatural beliefs. But spirituality, by its contemporary definitions, has evolved into a much broader scope to the point that some wonder if even the supernatural is at all referenced. Suggesting that

medicine ought to remain spiritually neutral for fear that it could inject theological bias and risk alienating physicians who either adhere to minority faiths or are atheists or agnostics, is received but not recommended. While avoiding spiritual matters may be the simplest and easiest solution for physicians it may not be the best. Several studies have reported patients indicating their preference for conversations about their faith with their physicians and health care providers. In accordance with the analytics as to whether or not spiritual and religious beliefs of the physician are important to patients, the results were strongly associated by race. Fifty-six percent of African-Americans agreed that this was important to patients, while 27 percent of whites and 17 percent of Asians agreed. The Association of American Medical Colleges (AAMC) suggest, “Physicians must be compassionate and empathetic in caring for patients...they must act with integrity, honesty, respect for patients’ privacy and respect for the dignity of patients as persons. In all of their interactions with patients they must seek to understand the meaning of the patients’ stories in the context of the patients, and family and cultural values.” This point is essential for the delivery of palliative care and crucial for African-American patients given what has been shared thus far.

So the question to further pursue is, “How does one go about integrating spirituality within the healthcare paradigm?” Chapter Five will explore the tools currently being utilized for screening and assessing patient spirituality. From a composite examination of these tools this dissertation will argue what may be the best approach to engaging African-American patients to mitigate mistrust and develop the physician-patient relationship in such a way to where spirituality can be freely discussed. There is agreement among scholars that due to the multidimensionality of spirituality, any model

used for its measurement and assessment must also be multidimensional.

Correspondingly, the care following the assessment should also be multidimensional and holistic which is consistent with policies around palliative care. For the purposes of research data applied to clinical practice it is essential to measure spiritual outcomes. However, as the number of tools have increased significantly there is thus far not much guidance in terms of what tools are best to use and in which situations to use them. Some tools have been considered culturally inappropriate. With the requests for culturally appropriate instruments for measuring spirituality scholars note that there is also not much guidance on how to be culturally appropriate for patients in general and in particular, those seeking palliative care for terminal or life-threatening illness.

One approach in bridging cultural dissimilarities and meeting patients where they are is through patient-centered care. Patient-centered care is a treatment modality that stands over and against disease centered or provider centered care and has become the focus of healthcare after a 2001 report from the Institute of Medicine. Some scholars have evaluated patient-centered care by the quality of the decisions made in the clinical setting. Specific to this point, it has been argued that physicians will at times decide what is the best course of treatment based on what makes medical sense and ignore patient preferences especially when there is multiple appropriate options. Where this began to come to light was the move by managed care organizations to control the rate of occurrence of some procedures by establishing criteria for when these procedures are appropriate to perform. When the choice between multiple treatment options has quality of life implications then it is critical to inform the patient to the fullest extent possible and allow the patient to participate in the decision making process. A new paradigm in the

conversation on patient-centered care is the patient-centered medical home (PCMH) concept endorsed by the American College of Physicians, the American Academy of Family Physicians and others as a way of addressing the disparities in current medical practice and optimal care. It is a team-based model, similar to the palliative care approach, with an emphasis on continuity of care, but with the following foci: a personal physician, whole person orientation, physician directed medical practice, coordinated and integrated care, quality measurement and improvement, payment reforms and enhanced access to care. This model is designed to facilitate active participation of patients in decision-making. It could be proposed that there is benefit to such an intentional structure. The population that would most significantly benefit from such intentional efforts of coordinated care would be those mainly underserved and that historically has had and continues to have high morbidity and mortality rates, namely African-Americans.

Since it is the goal of palliative care to alleviate patient suffering and since one of the areas physicians are mandated to examine is the spiritual needs of the patient then it is important that physicians have the means for making such assessments. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recommends that spiritual assessments be conducted but offers quite a bit of latitude as to the breadth and depth of the analysis but minimally suggest recording beliefs, practices and faith/denomination. The term spiritual assessment is generally used to describe the process and instruments used to ascertain the value and importance of spirituality and religion to the health and wellbeing of patients. There are three stages or approaches to ascertaining the spirituality or religious needs of patients: spiritual screening, spiritual

history and spiritual assessment. While a spiritual history can be considered an assessment in accordance with the minimal recommendation from JCAHO, some scholars look at it as separate from the actual assessment phase. One goal of spiritual assessments is to recognize spiritual strengths in patients as well as diagnose spiritual distress. Another goal of spiritual assessments is to identify how a patient's spirituality affects the types of service or care they may receive. Studies vary on who should and can conduct spiritual assessments on patients. Outside of the hospital chaplain, some have argued that nurses, social workers or physicians can conduct initial assessments. This can be extremely important for whomever conducts the assessment, outside of a clinical chaplain, because one does not want to run the risk of causing spiritual injury or exacerbating any spiritual distress a patient may be experiencing whether or not they are overtly exhibiting it.

There are a number of assessment tools that offer different benefits to the assessment practice as well as tools specific to ascertaining spiritual histories. These tools are 3H and BMSEST, PLISSIT, HOPE, FICA, SPIRIT, ecomaps, genograms, lifemaps, and ecograms. It has been suggested that when measuring spirituality in African-Americans it should be recognized that for many, their spirituality is and has been part of their daily life and not just in the moment of acute illness. Spiritual Histories are an invaluable asset to have in the clinical setting. It may be appropriate to find other ways or even other venues to reach out to African-American patients. In the African-American community the church has historically been the premier resource for the referral if not the provider of some direct social services. This has been so widely recognized that public health institutions have routinely used the church for health screenings, information

dissemination and exercise centers. Another institution that could provide assistance and even educational interventions are medical societies. These societies played a significant part in providing support for African-American physicians during heightened segregation and other discriminatory practices in U.S. history. Their work alongside the National Medical Association and the National Hospital Association was designed to push for opening access to hospitals for African-American physicians and nurses as well as the Black Hospital Movement. Many of these societies are actively engaged in the African-American communities today. Since these medical societies are already providing outreach in the underserved communities, conducting front line spiritual histories should be promoted and may be collected. With ever advancing technology these histories can be collected along with family health histories, and advance directives. This information can then be made part of the patient medical history, which can be retrieved, ideally electronically, by emergency department staff and attending physicians. With the spiritual history already collected, this information can serve as a baseline for further spiritual assessment if and when the patient's health condition becomes affected by chronic disease or terminal illness leading to the appropriate spiritual interventions.

Finally, in order to allow proposed plans and models for the delivery of quality palliative care to African-American patients, there must be intentionality and that intentionality must be sustained. It begins with recognizing and respecting the significant roles chaplains play in the healthcare setting and specifically with palliative care. Chaplains are too often used as bench players in the scientific world of medicine to fill in when the game is thought to be lost but they can and should play a more significant role in holistic care. In most clinical settings it is the chaplain who offers spiritual care. It has

been reported that higher levels of patient satisfaction, lower levels of anxiety upon discharge and shorter hospital stays resulted when patients were visited by a chaplain. Professional chaplaincy has changed over the past 50 years from a place where clergy who were considered marginally qualified were assigned to medical institutions to where we are today with professional standards including board certification. Although perceptions have improved greatly as this role has been professionalized, it is not yet completely where it should be. There are still some places where hospital chaplains are simply “on-call” congregational ministers. It should be strongly emphasized that the use of untrained community clergy to fill a role of offering spiritual and pastoral care to patients in crisis is unethical because it violates the rights of palliative care patients to receive quality physiological, psychosocial and spiritual support. However, members of various hospital departments view the role and importance of the hospital chaplain differently. Knowing when to refer to the chaplain is important in the provision of quality patient care. With an interdisciplinary team, which is the model used in delivering palliative care, efficiency in providing care is only possible when roles are clear and mutually respected. Some role confusion results from the lack of understanding and recognition of the extensive training required of chaplains in order to become board certified. In addition to at least three years of theological study, one must also acquire 1,600 hours of supervised clinical pastoral education (CPE). Four hundred of these hours involve studying world religions, the disease process and interpersonal skills development. Current CPE educational standards recognize this and as mentioned earlier cultural competency is required for board certification. The United States is home to various ethnic groups and people from a variety of cultural backgrounds. Current CPE

educational standards recognize this and cultural competency is required for board certification.

Cultural competence is said to go beyond cultural awareness and cultural sensitivity, terms often used in the discourse of multicultural relations. Various terms have been used in reference to cultural competence such as cultural sensitivity, cultural responsiveness, cultural effectiveness which indicates a lack of consensus on how to frame a strategy in addressing health disparities and the need for quality care among racial/ethnic populations. The Institute of Medicine has emphasized the need for cross-cultural training in enhancing the quality of care and eliminating disparities among racial ethnic population. While this emphasis from the Institute of Medicine expands the scope of attention on the need for cultural competence beyond the relation between white and non-white physicians with African-American patients, care should be taken to not dilute the urgency and seriousness of these relations specifically. The history of inequities and mistreatment of African-Americans in this country is sound reason for the advocacy of the continued responsible treatment of African-American patients by physicians who do not share this cultural heritage especially if the goal is to reduce if not eliminate healthcare disparities among this population.

It has been reported in some literature that the prolonged impact of racism has been linked to poor health outcomes of African-Americans. It has also been recorded in the literature that many minorities, especially African-Americans underutilize hospice and those who have used it have expressed dissatisfaction with end-of-life care. While representing 13 percent of the U.S. populations, African-Americans only make up between 4 and 9 percent of hospice patients. There is a correlate between the views of

African-Americans towards completing advance directives, discussing end of life issues, continued life sustaining treatments and hospice utilization. Recognizing the emphasis on cultural competency as a strategy for addressing racial/ethnic healthcare disparities, it should be noted that there are organizational, structural and clinical barriers that make cultural competency interventions difficult. There are also structural barriers that affect people of low socioeconomic status regardless of race or ethnicity; however, there are some that particularly affect minorities such as lack of interpreters in multilingual contexts, bureaucratic intake processes, and continuity of care through the specialist referral process. The latter two would apply to African-Americans more than language concerns although respect for comprehension level has been mentioned in other literature. African-Americans are disproportionately poorer than non-Hispanic whites in the United States. The cost of healthcare is a structural barrier for most people but especially for people with low socioeconomic status (SES). Because of cost-containment priorities of managed care, insurance companies are selective in what types of treatments or therapies they will cover. Evidence exists that for African-Americans, who are systemically exposed to social disorder and violence typically found in low-income, segregated communities there is a high risk of chronic and cognitive disease due to the associated allostatic load. Clinical barriers are the unwillingness to accept, appreciate, understand and explore the socio-cultural differences between the clinician and the patient or patient's family during the clinical encounter. Such barriers negatively affect communication and trust. African-American mistrust with the healthcare system is well documented.

Staffing diversity is an issue that can either stifle efforts to address cultural competency or support these efforts. In 2003 the American College of Physicians wrote a position paper in which they recommended increasing the number of minority physicians as a way to reduce health disparities. Yet the health disparities continue to exist even today and the number of African-Americans in medicine has not appreciated much either. According to a 2015 report from the Association of American Medical Colleges the number of African-American male applicants to medical schools has declined below 1978 numbers. In 1978 there were 1,410 applicants; in 2014 there were only 1,337 despite increases in African-American college graduates. In addition predictions estimate a shortage of physicians between 46,000 and 90,000 by 2025 amid a more diverse population. But minority physicians are not only needed to care for the minority population; they may also serve as mentors to those entering or considering entering the field of medicine. Addressing the demographics of faculty in medical schools is equally important. Literature supports the argument that the inclusion of racial/ethnic physicians among a medical faculty, or in other words, underrepresented minorities in medicine (URMM), helps medical students and other members of the faculty enhance their awareness and appreciation of cultural differences thereby improving cultural competence through the sharing of their knowledge and worldview as well as the mentoring of students and residents. Despite the frequent discussions on the value of recruiting and retaining underrepresented minorities as faculty in medical schools the numbers continue to indicate there remains much work to be done. Over a 20-year period from 1981-2001 the number of URMM faculty in U.S. medical schools more than tripled from 1,140 to 4060 but even this only represented 4.2 percent of total faculty nationwide.

Twenty years later the percentage of minority faculty has risen to a disproportionate 7 percent of a total census of now 130,000 faculty. However, even for those who are hired in these roles, the academic environment has not been a pleasant experience for a number of them.

Palliative care is committed to holistic care and one of its foundational structures is spiritual care. As important as cultural competency is to the delivery of quality care, so too is the corresponding understanding of the spiritual beliefs, practices, and possible effects spirituality can have on patient decision-making, health outcomes and well being of family members. Physician experience in interacting with racial/ethnic patients and recognizing possible signs of spiritual distress should first be learned in medical school. This knowledge and experience is critical in the provision of quality palliative care. In a study of medical students at Harvard affiliated hospitals without required palliative care rotations, eighty-eight students were surveyed in their last four months of the 2012-13 academic year. In this survey, 26 percent of the students never cared for a patient who died, 55 percent never delivered significantly bad news, and 38 percent never worked with a palliative care clinician. Of the 74 percent of students who cared for a dying patient, 84 percent had one or more patient deaths that were not followed up with a debriefing and 56 percent of the students who cared for a dying patient were never debriefed. In terms of student evaluations of training, 83 percent of the eighty-eight students who responded to the survey expressed the desire for more education on caring for dying and terminally ill patients. Also almost 50 percent of the students reported caring for dying patients is depressing and 37 percent reported they would feel guilty if a patient died, and 24 percent stated they would be hesitant to face the emotional distress of

family members of a dying patient. This information supports the proposal that spirituality courses in medical school curricula should be more extensive than covering the anthropology of religion. To address these concerns and to foster the learning environment in which the technical and human aspects of palliative care can be integrated the Weill-Cornell Medical College created a clerkship in ethics and palliative care, which uses the reflexive techniques. It involves relieving the student of the responsibilities of clerkship so that they can engage the humanistic dimension of practice. Also because students, as well as other clinicians may at times experience strong emotional reactions early in their encounters with dying patients this offers them time under supervision to identify their areas of discomfort.

Finally, programs implemented to address the health disparities have typically focused on cultural competency and cross-cultural communication skills but the success of these programs are limited by their lack of depth in recognizing and dealing with unconscious cognitive processes. How much of an influence the historical development of racial prejudices has had on decision-making of whites that involve African-American subjects has been recently explored in the area of social cognitive psychology and is referred to as implicit and explicit bias. It is what affects the way people process information. Evidence of implicit bias can be found in the legal system, law enforcement, as well as in the healthcare system. The Implicit Association Test (IAT) has been used in cognitive research since the 1990s. It is designed to pair an attitude object with an evaluation marker. For example, the attitude object can be a racial group while the evaluative marker could be “good” or “bad” and the speed in which a person taking the test pairs the object with the marker determines the strength of an attitude. In the first

study where the IAT was used in a healthcare setting, 287 internal medicine and emergency residents were given the test to predict the affect of implicit bias on the recommendation of thrombolysis for acute myocardial infarction in white and African-American patients. It was discovered that 67 of the participants found out what the study was about and therefore their results were excluded from the analysis. One of the IATs administered was the *Race Preference* IAT. The output scale ranged from about -.6 to 1.2. The negative range correlated with “problack” bias, “0” related to no bias, and positive numbers correlated with “prowhite” bias. The results of the test revealed the following: African-American physicians scored near zero while others had scores in the positive “prowhite” range. Also, as the scores increased on the scale toward “prowhite” the recommendation for thrombolysis decreased indicating a significant correlation between patient race and implicit bias. Several other things were revealed as well. For those 67 participants who expressed foreknowledge of the premise behind the tests, as their bias increased, their propensity to recommend thrombolysis to African-American patients also increased thereby supporting the reason for excluding their results from the analysis. Implicit bias measurement results do not expose overt racism but they do remind us that people with the best of intentions have an unconscious compass that may influence surprising results in their decisions in surprising ways. Finding opportunities to integrate implicit bias training into the pedagogy in medical schools along with programs and instructions on cultural competency may not only begin to eliminate disparities in health and healthcare for African-Americans but may also begin to abridge the distrust.

Chapter 2. The Development of Palliative Care

2.1 The History and Background of Palliative Care

When the subject of Palliative Care is discussed it cannot be done without mentioning the works of Dame Cicely Saunders. Saunders has been extensively credited for her pioneering works in the area of quality of life for dying patients and as well as the founding of the first modern hospice. The United Kingdom (UK) was the site for this groundbreaking work when Saunders was a research fellow at St. Joseph's Hospice in 1959.¹ Her focus was on the care of dying patients, primarily those dying from cancer. The focal point of medical professionals at the time was centered on how cancer might be cured in a patient and once the malignancy became too advanced little attention was then offered to the patient. At that point the patient was released to die at home.² But the accompanying pain was not properly managed, and as a result, patients were suffering immensely unto death. In her earlier days at St. Joseph, Saunders challenged the prejudiced position of physicians and restrictive regulations regarding opiate dispensing fearing patient dependency. Saunders retorted that if pain was managed, other areas of the human condition could then be addressed.³ Her strong Anglican background, coupled with the religiously accommodating environment of St. Joseph's allowed Saunders to broaden her interest beyond physical distress to the mental distress eventuated by pain.⁴

Throughout the early 60's researchers began trying to analyze the needs of patients suffering from the effects of terminal cancer, researchers such as Eric Wilkes in the field of medicine as well as John Hinton, Colin Murray Parkes and Elisabeth Kubler Ross in the field of Psychiatry.⁵ The quality of care for patients in hospitals, once

treatment for cancer exceeded curative hopes, was severely lacking. This led Saunders to develop a nuanced specialty focusing on the care of patients dying from cancer and in 1967 Saunders, with the assistance of others, founded St. Christopher's Hospice, considered advanced in comparison to other hospices at that time in the UK. It was here that symptom management began to take root with a particular concern for the physical, psychological, spiritual and social elements of patient life.⁶ Within the context of symptom management was the brilliant focus of pain management. The "Brompton Cocktail" was the analgesic elixir of choice at the time. It was a combination of morphine and cocaine later scrutinized by Saunders' colleague at St. Christopher's, Robert Twycross.⁷ As a result more attention and research in different ways to administer morphine and other analgesics began to unfold. Care for the patient in an irreversible and unretractable terminal condition was now the focus de jour in this unfolding world yet to be called "palliative care." According to Diego Gracia, Professor of the History of Medicine and Bioethics at the Complutense University in Madrid, "The true goal of medicine has always been curing, rather than taking care of the patients. Caring has never been the goal of medicine."⁸

Many had embarked on the journey of discovery into the world of pain focusing primarily on the distinctions between the acute, cancer, terminal and chronic variety, during the same time Saunders was researching in the St. Mary's school of Pharmacology - scholars such as Bonica, Beecher and Maher.^{9,10} Pain management and the associated psychosocial needs are what attracted many to work with Saunders and her colleagues at St. Christopher's Hospice because a new caring strategy was being presented. David Clark's analysis of Cicely Saunders' early writings expounds on her remarkable

contribution to the discourse on pain. Her identification and classification of “total pain” laid the groundwork for future work in exploring the multiple dimensions of pain – physical, psychosocial, emotional, and spiritual.¹¹ This concept was germinating in the scholastic work of Saunders even before the interdisciplinary care model was launched at St. Christopher’s. According to Clark, Saunders’ ethos, consisting of the professional mixture of social work, nursing and medicine, steered a treatment modality beyond “symptomatology” to delving into the meaning of pain. He further adds that there are pains that analgesics cannot ameliorate and each is a layer beyond physiological manifestations.¹²

Although the term “palliative care” was never used in any of Saunders’ work her philosophy background enabled her to understand the historical and evolving concept of palliation. For Saunders palliation needed to be invoked when curative measures were no longer effective and prior to the patient’s condition becoming “terminal.” Saunders’ practice was terminal care and her diagnosis was “total pain.”¹³ Clark sees this use of pain as a “key to unlock other clinical possibilities.”¹⁴ What we now have is a psycho-spiritual therapeutic addendum to the medical rubric of care being applied as a treatment for the whole person, as the patient, free of pain, is able to express the meaning of his or her current state of suffering. This is what was carried to St. Christopher’s Hospice. The quality of life for a patient suffering with pain that resulted from a terminal malignancy was being explored rigorously.

The influence of St. Christopher’s on the development and expansion of hospice care, throughout the UK and elsewhere in Europe, was evident. Over the next 20 plus years, hospices sprouted; however, there was not much uniformity in configuration or

application of service. Some tried to replicate the St. Christopher's model while others sought to improve upon it.¹⁵ While the hospice movement was in motion, some hospitals began creating terminal care support teams. The first to do this was St. Thomas's Hospital in London in 1976.¹⁶ During this same time period, hospital based home care was started in Sweden as an alternative to hospital care, supporting the desire expressed by most patients to be at home during their final days. Hospital based home care expanded to Spain in 1980 and in Brussels in 1985 with the establishment of the Continuing Care organization.¹⁷ Inpatient palliative care and hospice services also started in many hospitals across Europe. In the United States (U.S.) hospice and palliative care services developed later. Whereas the hospice movement in Europe had its origins in the field of oncology, and likewise its descendent, palliative care, oncology was less integrated with hospice care in the US. Palliative care did not become a focus in the US until the 1990s.¹⁸ The hospice movement in the US started as a standalone entity, as a replication of what was underway in the UK. Unlike its European counterparts, hospice care in the US began as home care in Branford, Connecticut in 1973.¹⁹

The creation of hospital support teams in the UK subsequently became multidisciplinary palliative care teams and in some cases palliative care nursing specialists sprouted as early as 1982. By the 1990s with the help of the Marie Curie Memorial Foundation and its palliative care centers and the Macmillian Cancer Support Center, the number of nurses trained in palliative care grew significantly.²⁰ One cannot under appreciate the contribution of nurses to the development palliative care. As palliative care was slowly developing nurses who gravitated to this field did so from the unction emanating from their own morals and values and not so much for academic

pursuits or professional rewards – the values and morals at this time being predominantly Christian-based.²¹ The creation of district nurses in the UK, offered day and evening services for cancer patients under the National Health Service in nursing homes and other facilities purchased by the Marie Curie Cancer Care, formerly known as the Marie Curie Memorial. Even today district nurses care for the majority of terminally ill patients receiving home care in the UK. They offer a form of ministry of presence according to Woods because families appreciate the fact that the nurses are “there for them.”²² The establishment of international associations provided the professional focus needed to garner wider attention across the European landscape, the earliest of which was the European Association for Palliative Care in Milan, Italy in 1988. The formation of the International Hospice Institute in 1980 expanded and became the International Association for Hospice and Palliative Care in 1999.²³ Other associations continued to form across Europe but what became apparent was that information on the development and progression of palliative care throughout the countries was somewhat unreliable, as implementation strategies appeared inconsistent. In 2003 the European Association for Palliative Care, at the action of its board, created the EAPC Taskforce on the Development of Palliative Care. Its mission was to “research palliative care developments in the European region including all the countries that make up the World Health Organization (WHO) European Region, a total of 52 countries at that time.”²⁴ In 2008, in an effort to influence national and regional policies, the EAPC launched a Europe-wide Delphi study. The mission of study was to acquire consensus data around standards and norms in palliative care across Europe. Participants in the study included were individual EAPC members representing 40 countries as well as representatives from

national hospice and palliative care associations. One of the things challenged was the WHO definition of palliative care. The EAPC created its own definition for palliative care, stating specifically, “Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.” This definition was overwhelmingly supported by the participants but also criticized for its length.²⁵

Despite this effort, what remains a challenge in Europe is the means in which to implement standards across the European enterprise given the disparate levels of health care access between countries, the varying stages of palliative care development between countries, as well as the cultural and language differences.²⁶

In the U.S., similar to what took place in Europe, hospice affiliate associations expanded their emphasis to include palliative care. One such organization was the National Hospice Organization, which later became the National Hospice and Palliative Care Association. A distinctive driver in the U.S. was the hospice eligibility restriction. Patients whose terminal status did not meet the Medicare requirement of 6-months or less were not eligible for hospice care. This led to the growth of palliative care teams in US hospitals enabling them to provide symptom management to patients with longer life

trajectories.²⁷ Within the medical profession there was also a similar expansion when the American Academy of Hospice Physicians became the American Academy of Hospice and Palliative Medicine.²⁸ This latter development showed a growing acceptance for palliative care in the US.

Un-tethering palliative care from the confines of terminal care was a slow developing reality. However, according to Pickett et al., in the 90s the challenge was getting clinicians to see the opportunities to provide palliative care outside of hospice.²⁹ Since then over a 10-year period, palliative care programs grew, primarily in the hospital settings and apart from hospice delivery, because of the need to provide symptom management to patients who were not classified as terminally ill.³⁰ Due in part to the 1995 Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), private funding jump-started several initiatives for palliative care development. This study revealed that many patients in the US suffered unnecessarily from the lack of pain management and that the wishes of patients were often ignored or misunderstood by physicians.^{31,32} In response, funding from the Robert Wood Johnson Foundation led to several significant projects perhaps the most significant being the Center to Advance Palliative Care. A published report by the Center entitled “The Case for Hospital-based Palliative Care” offered the salient argument for integrating palliative care into acute care situations.³³ This extended understanding of palliative care will be applied within the context of this dissertation.

In 2001 the National Consensus Project for Quality Palliative Care was established in the US through the collaboration of five hospice and palliative care organizations across the nation including, the Hospice and Palliative Nurses Association

(HPNA), the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Last Acts Partnership and the National Hospice and Palliative Care Organization (NHPCO). In an effort to establish standards for palliative care they established a set of guidelines. The standards are the *Clinical Practice Guidelines for Quality Palliative Care*. Palliative care development received a boost in 2010 with the passage of the Patient Protection and Affordable Care Act. Provisions in this bill allowed for children covered by Medicaid or enrolled in the Children's Health Insurance Program as well as adults enrolled in Medicare Part A to receive concurrent hospice and curative treatment.³⁴

2.2 Definition of Palliative Care

As mentioned previously, the term palliative care did not exist until Dr. Balfour Mount of the Royal Victoria Hospital in Montreal introduced it. There is no absolute definition of palliative care. To some it equates with hospice and end of life care, while others share an extended definition which views it as not only end of life care but also continuity of care for the chronically ill.^{35,36,37} The key to palliative care, according to Boitte, is to "introduce interdisciplinarity into the usual functioning of multidisciplinary team."³⁸ Palliative care in its earlier developments was almost indistinguishable from end of life care because of its melding with hospice care, focusing on the dying.^{39,40} In 1990, the World Health Organization described palliative care as follows: "Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families."⁴¹ According to Gracia, palliative care was seen as a

response to aggressive treatment or overtreatment of terminally ill patients.⁴² This harkens back to Gracias' earlier comment that the goal of medicine was to cure as opposed to care. Henk ten Have has a contrary view. He states that palliation has always been a goal in medical care.⁴³ This brings into tension the distinction between medicine and medical care. For Illhardt, this dialectic is also at the heart of the ambiguity regarding which category palliative care should fall.⁴⁴ He further conveys the point that the discrepancy in terminology further adds to the ambiguity as well suggesting palliative care has been used derogatorily, metaphorically, in competing as well as medicalized ways. The transition from curative to palliative can present as a tug of war rather than a handoff or symbiotic interplay. Illhardt views the integration of palliative care within the context of medicine will reduce its efficacy to control and constrain overmedicalizing terminally ill patients. Janssen agrees and suggests that palliative care has a distinct axiology different from that of curative medicine, which in itself is an ethical journey.⁴⁵ The idea of medicalization coincides with the increased use of technology with patients in the "terminal phase" as evident in hospice. From this viewpoint of Illhardt and that of Giorgio Di Mola⁴⁶ this appears to be a threat to the original principles upon which the hospice movement was founded.

While some of this extensive treatment is due to the physicians' quest for success, another part of it is due to families and medical personnel not knowing, or, knowing and not being willing to follow the wishes of the patient. And so the quality of life for the terminal patient deteriorates, near life's end. Atul Gawande, a Harvard surgeon and public health researcher, shared in his New Yorker article that there are the struggles with knowing when the battle for life has been lost.⁴⁷ In 2002 the World Health Organization

(WHO) redefined palliative care as “an approach which improves the quality of life of patients and their families facing life threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual.”⁴⁸ What can be seen from this revision in definition from the WHO 12-years later is the obvious shift in focus from “disease not responsive to curative treatment” to disease that is “life threatening.” This latter definition does not assume the disease cannot respond to treatment, which suggests the integration of palliation closer to disease diagnosis and concurrent with curative therapy.⁴⁹ However, to be clear, according to Findlay, what sets palliative care apart from curative treatment, is that the former focuses on the consequences of a disease while the latter focuses on the causes and cures.⁵⁰ The EAPC, as mentioned previously, in its study to develop data for consensus on palliative care norms and standards and in creating its own definition for palliative care, took exception to the WHO’s use of the term “impeccable” stating that it was too “inadequate and unrealistic.”⁵¹ Jünger, et al. also made the point that among the experts that participated in the EAPC study, some were making a distinction between supportive care and palliative care, that supportive care was strictly confined to the discipline of oncology. But even in this area there were varied opinions.⁵²

Further dilemmas exist in defining palliative care due in part to the increasing integration into the traditional healthcare framework. With the insertion of palliation along the continuum from diagnosis to death, the variety of institutions in which palliative care is offered, and the increasing number of diseases and condition states within the disease, ambiguous nodal points triggering palliative care arise. Ten Have

argues that the variety of palliative care services along with their inconsistencies stem from the palliative care movement and the splintering from its origins in hospice care to serve the needs of patients in various locales. Further, the movement itself recognized the need for being integrated into the healthcare framework.⁵³ What we then have is a demarcation dilemma, which then creates an ethical conundrum because such ambiguity can foster inconsistencies in care. Rien Janssens, et al. state, “an ethical analysis of palliative care should be based on conceptual clarification and conceptual clarification in its turn is at least in part an ethical enterprise.”⁵⁴ This is based on their premise that issues such as pain management, quality of life, and autonomy are either ambiguous or have been analyzed predominantly from a medical prism while palliative care is not constricted to only a medical worldview. This is especially true as palliative care distinguishes itself from other medical disciplines by focusing not only on the patient but also on the patient’s family, not only on the medical treatment, but also the psychosocial and spiritual dimensions of both stakeholders.

The National Consensus Project for Quality Palliative Care has been deliberate in its efforts to draw attention to the value in improving the quality of palliative care and in the process established a set of reputable guidelines. One of the other objectives of this project is to promote the integration of palliative care into all health care for “persons with debilitating and life threatening illnesses,” in order that: “pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.” In addition, the Project views palliative care not only as a specialty but also as “general approach to patient care that should be routinely integrated with disease-modifying therapies.”⁵⁵ Other supports for integrating

palliative care at the time of the diagnosis of serious illness suggest that during this time patients and families often face distress; therefore, in order to establish adequate goals of care the need for palliative care is crucial.⁵⁶

A consequentialist view of care calls for a discussion around quality of life. When the subject is end of life then a term often used with this quality of life framework is “good death.” Kathryn Proulx, a psychopharmacologist, and Cynthia Jacelon, an associate professor and clinical nursing specialist, state that a good death includes: “peacefulness, physical comfort, autonomy, preparedness, connectedness with loved ones, awareness, discretion, meaning and acceptance.” and they equate a “good death” to dying with dignity. They further state, referencing Richard Gamlin’s article in the *European Journal of Palliative Care*, that the “experience of dignity might change across different stages of illness, making effective communications between patients, family, and health care providers essential.”⁵⁷ If a good death is considered dying with dignity and if it is to include all of the aforementioned attributes, then the question must be asked, “Is it a bad death if one or more of these attributes are missing? Again, this is an example where palliative care is narrowly equated with end of life care.”⁵⁸ However, if palliative care is the approach to improving quality of life, generally speaking, and if by quality of life we refer to peacefulness, physical comfort, autonomy, preparedness, connectedness with loved ones, awareness, discretion, meaning and acceptance, then it is important to examine how spirituality is viewed as an important element in assessing care and in the delivery of care within the palliative care framework. Therefore it is only logical to examine the role of spirituality in achieving the goal outlined above.

One challenge for this definition of palliative is patient autonomy and the relativity of awareness, which proves problematic for Alzheimer patients. Obviously, patients with dementia and Alzheimer's eventually lose their sense of awareness, raising the question how then is quality of life improved for these patients through palliative care. Palliative care has long been associated with patients suffering from cancer and other chronic illnesses but Alzheimer's disease is in the margins of discussions regarding the appropriate form of care.⁵⁹ Care for Alzheimer patients and others in the margins of palliative care research and practice also reveals new ethical dilemmas, which will be addressed later in this chapter when the ethics of palliative care is explored.

Dekkers notes that in trying to add clarity around palliative care, much attention is given to the definition of palliative care, approaches in palliative care and the foundations of palliative care. However, what is equally important is a discussion around the goals of palliative care, which he likens metaphorically to "a patient's home coming."⁶⁰ He expounds on several possible meanings for this metaphor: (1) one's own home, (2) a homelike environment, (3) one's own body, (4) a spiritual environment, and (5) the origin of human existence.⁶¹ While the comprehensive analysis of the metaphor is appreciated in this exposé, what is most germane in linking the value of palliative care to African-Americans is Dekker's commentary on the spiritual environment. Particularly, Dekkers notes that for hospice patients home is referenced as a safe place, a place of "spiritual familiarity and security."⁶² Given the evidence that most patients that are terminally ill would rather die at home also supports the reference to feeling secure in a familiar place. For African-Americans a few things are at play. African-Americans, when a family member dies will have what is called a "home-going" service.⁶³ The phrase "going

home” is a vernacular commonly used by African-Americans who are terminal and are ready to die. In the chapter on religion and spirituality this will be examined in more detail.

2.3 The Role of Spirituality in Palliative Care

Spirituality is one of the trilateral components of palliative care alongside physical and psychosocial support. Unlike any other field in healthcare, training in the relevance of spirituality and religion within the practice of palliative care is important.⁶⁴ It should also be noted that although spirituality and religion are often referred interchangeably, there is a difference.⁶⁵ In the succeeding chapter on Spirituality and Health care this difference will be examined in more depth. Washington and London say, “Spirituality is an inner search to find meaning and understanding of universal questions of human existence” whereas “religion is a set of structured guidelines and beliefs that are practiced within a religious tradition or institution...Religion is structured around doctrines that propose answers to the universal questions of spirituality.”⁶⁶ This metaphysical definition is considered a secularized version of its traditional Christian origin, a shift in focus from who we are in relation to God to a personal purpose and meaning even without Godly relevance.⁶⁷

There could be little coincidence with this shift in definition and the philosophical movement in Europe in the area of pain and suffering. During the first quarter of the 20th century the idea of self-discovery through pain and suffering emerged in France. This followed works of German psychiatrists and philosophers Karl Jaspers and Martin Heidegger who saw suffering as an existential summit.⁶⁸ Later Austrian psychiatrist Victor Frankl produced his seminal work “Man’s Search for Meaning.” Sociologist Tony Walter

states that Cicely Saunders, a student in philosophy herself, picked up on Frankl's self-expression of suffering and applied it to the palliative care discourse and in doing so took the liberty to superimpose spirituality as that search for meaning rather than what Frankl described as existential.⁶⁹ What will be argued later is this secularization of spirituality is incongruent with the history and practice of spirituality for African-Americans.

A number of studies have indicated that patients suffering from terminal and other advanced illnesses view spirituality and religion as very important to them in helping to cope with their condition.^{70,71,72} However, incorporating spirituality in the delivery of care has been met with resistance or has been minimally attended to despite evidence supporting patient reliance.⁷³ For spirituality to be effectively integrated within palliative care it is important to understand the role of all medical professionals in this integration. Since its inception the palliative care paradigm in health care delivery has been a team approach but to some scholars the integration of spirituality has been controversial with many health care professionals still searching for its relevance.^{74,75,76} Some medical professions avoid inquiring about a patient's spirituality because they view such an inquiry as an invasion of privacy. On the other hand it is believed that the quality of the care offered to terminally ill patients correlates with how medical professionals reflect on their own spirituality because this may allow the caregiver to comfortably enter into a dialogue with the patient about the influence their spirituality has on their medical decision-making.⁷⁷ According to Olson et al., "openness to discussions of spirituality contributes to both better health and better physician-patient relationships."⁷⁸ So, spirituality in this context is not only important for the patient, but also for the caregivers, professional and non-professional because it can help them deal with resulting stress

effectively.⁷⁹ With respect to palliative care specifically, for medical professionals to not acknowledge the importance of patient spirituality or even its legitimacy and its impact on the patient's medical decision-making, violates their ethical responsibility.⁸⁰ For African-Americans, Barrett, et al., state, "It is almost unthinkable that you can have an honest, intelligent discussion about death and dying, unless you deal with the centrality of spirituality in the black experience."⁸¹

Dr. Daniel J. Sulmasy, professor of medicine and ethics, suggests one way to bridge the difficulty medical professionals face in confronting the integration of spirituality in patient care should begin with understanding medicine as a spiritual practice as it attempts to mitigate the injury to the "embodied spiritual" body that disease causes.⁸²

The guidelines established by the National Consensus Project for Quality Palliative Care specifically are organized into eight domains: (1) Structure and Process of Care, (2) Physical Aspects of Care, (3) Psychiatric and Psychological Aspects of Care, (4) Social Aspects of Care, (5) Spiritual, Religious and Existential Aspects of Care, (6) Cultural Aspects of Care, (7) Care of the Imminently Dying Patient, and (8) Ethical and Legal Aspects of Care. Several important things lifted up in the 5th domain are that medical professionals should regularly investigate the spiritual and existential concerns of the patient and family, provide and evaluate spiritual interventions that are culturally relevant and consistent with the faith tradition of the patient and family.⁸³

Walter raises an interesting argument regarding the necessity for medical professionals to feel obligated in providing care, to also tend to the spiritual needs of patients. Basing his argument on a 1999 advertisement for a spiritual care workshop at St.

Christopher's which read, "all health professionals working in palliative care share responsibility for the spiritual needs of patients and families," Walter believes such an assumption creates an unwelcome burden on medical personnel, especially since they are the least skilled at addressing spiritual needs of patients.⁸⁴ However, O'Donnell believes that despite a lack of comfort or competence, it is the responsibility of health care professionals to acknowledge its reality and assist patients as they explore their spiritual interests in the context of their care.⁸⁵ For theologian Marie Giblin, effective palliative care requires less technical expertise and a more professional willingness to share in the experience of human suffering. She continues, that to accentuate and expect professionals to only operate in their area of expertise and not become caring companions "medicalizes the dying process," "disempowers everyone" on the team and "heightens the isolation" of the patient.⁸⁶ When the medical professionals are unable to follow through with the care plan for the patient, including spiritual support, because of misalignment in personal values or spiritual/religious beliefs with the patient, an ethical dilemma results. These ethical dilemmas cannot only be personal but institutional as well. Ethical implications will be examined further in the next section. According to O'Donnell, it is the responsibility of the medical institution to foster a work environment responsive to the spiritual needs of patients and the responsibility extends to administrative staff.⁸⁷ By using the term "spiritual care" as opposed to "chaplaincy care" or "pastoral care" it implies a universality of responsibility. The latter two terms are discipline specific with "pastoral care" being more Christian centered. Therefore as board certified chaplain and consultant George Handzo states, "all health providers have a role in spiritual care as all providers have a role in emotional care."⁸⁸

2.4 The Ethics of Palliative Care

In addressing the ethics of palliative care it is important to review the definition of palliative care that will be the basis for ethical analysis throughout the dissertation. This section will present the ethical obligations and challenges in improving the quality of life and relieving pain and suffering for patients and their families. Health care is a system while palliative care is care delivery mechanism that is team oriented and patient centered. As patients face life-threatening illnesses, palliative care needs to exhibit the nimbleness and flexibility to adapt to the uniqueness of each patient as opposed to the patient adapting to the care available. Therefore, to think of palliative care as a philosophy of care, as reported by the National Consensus Project for the Palliative Care in their summary report,⁸⁹ is to run the risk of palliative care becoming an ideology as Pellegrino warns,⁹⁰ and could silence the voice of patients and their families severely affecting medical decision-making.

Medical ethics, the product of the conjoining of theological and philosophical worldviews has become its own enterprise. As opposed to an objective application from the periphery of medicine it now adds a consultative dimension from within being heavily influenced by the scientific methodologies of medicine.⁹¹ Janssens further suggests the need to consider an ethics of palliative care differentiated from medical ethics. One of the things not often mentioned when addressing the ethics of palliative care is the ethics of virtue or personal character. Pellegrino, et al., state that the combination of what had been described as natural and supernatural virtues are what laid the groundwork for virtue ethics. The natural virtues are those characteristics guided by reason and unaided by Scripture, compelling the person to seek the good while the

supernatural virtues are aided by Scripture.⁹² However, it was during the Enlightenment when “the center of gravity of ethics shifted from the kind of person one ought to be to the kind of decisions one ought to make, from the virtues one should cultivate to the principles, duties, and rules one ought to respect.”⁹³ Since spirituality is one of the critical areas of focus within palliative care it would seem only natural to adjoin the relevance of virtue and character. Giblin calls us to expand our principles-based ethical frameworks to include virtue when evaluating end of life care. For Giblin, relationships are an important driver in palliative care and even more important with hospice care. Thus the virtues and personal character of medical practitioners will determine if and how those relationships develop.⁹⁴ Virtue ethics is less about the act or the decisions of right and wrong and more on the traits of the person that lead to the decisions made or acts committed. In referring to the Hippocratic Oath it can be seen how purity and piety are promoted where it is stated, “In purity and divine law I will carry-out my art.”⁹⁵ Pellegrino, et al., reminds us that the principled nature of medical ethics, as it is now practiced – what is referred to as *quandary* ethics, focuses more on the process of decision making and therefore offers little in the discourse on “the right and proper conduct of physicians.”⁹⁶ While the subject of principles and duty or deontology pervades discussions on health care, there is a comfortable platform for relevant injections of virtue within dialogues on palliative care and specifically end of life care. This area of ethics is critical in the analysis of palliative care as we discuss impediments to optimum care for populations in general and African-Americans specifically.

Another important ethical issue for palliative care is access. From 2000 to 2011 the number of hospitals in the U.S. with palliative care programs increased 138%.

However, implementation across the 50 states is inconsistent. 80% of the hospitals in the District of Columbia and 7 other states have palliative care programs while this is true in only 20% of the hospitals in Mississippi and Delaware.⁹⁷ Despite the overall improvement in the number of hospitals with palliative care programs, the fact that there are some patients who are potentially denied this type of care in certain parts of the country creates an ethical dilemma. What seems to be even more problematic is that if the general public in some of the states with less saturation are not benefiting from palliative care, for African-Americans this inaccessibility to care can be even more acute given the fact that generally speaking African-Americans are more likely to receive substandard care for a variety of reasons including but not limited to racism⁹⁸ and cultural incompetence.⁹⁹ According to a state by state report card published by the Center to Advance Palliative Care and the National Palliative Care Research Center¹⁰⁰ along side 2013 population estimates from the US Census data¹⁰¹ of the 17 states in the South with an African-American population above the average of 22%, only Maryland and North Carolina were rated a B or better in the percentage of hospitals with palliative care programs. In the 9 states of the Northeast all were rated a B or higher. The average population for African-Americans in these states is 8.3%.

2.4.1 Personal Autonomy and Palliative Care

Personal autonomy is one of the four bioethical principles in the original discourse offered by Beauchamp and Childress, principles that have found significant traction within ethical analyses of western medicine. In the area of palliative care, autonomy teeters along the tightrope between *merely alive* vs. *meaningfully alive*.¹⁰² However, Riens Janssens, et al. claim these principles do not seem to hold high value

within the conceptual framework of palliative care. For example, it is stated that in the report from the European study examining the moral values in palliative care, as part of the 1999 Pallium Project, these four principles received considerably low rankings in comparison to other “moral notions” such as quality of life, human dignity and the acceptance of human mortality; yet, the data from this project report more than 75% of the respondents considered them important.¹⁰³ Based on the Greek words *autos*, meaning self, and *nomos*, meaning law or rule, autonomy is simply the ability to self-rule or to have the authority to make choices free of interference or external control. According to Beauchamp and Childress, no decision is fully autonomous; rather, they are “substantially autonomous” because no decision is completely free of influence. They go on to say that full autonomy is a “mythical ideal.”¹⁰⁴ In the area of health care, personal autonomy is a response to paternalism and is expressed through the use of living wills, advance directives and informed consent. In palliative care settings, especially with patients for whom death is imminent, the patient as well as the family may find themselves under emotional distress and unable to rationally decide what is in the best interest of the patient. In this case medical personnel should be cognizant of and sensitive to patient and family vulnerability.¹⁰⁵ This is most importantly why patients deserve full disclosure from their doctors about their condition, their prognosis, available treatment options as well as any side effects, if any, in a manner understandable by the patient. Although, it is possible that consent with full understanding could be a challenge for some palliative care patients.¹⁰⁶ This, in essence, is the basis for the bioethical principle of respect for autonomy. However, it assumes that the patient has decision-making capacity. In the event decision-making capacity is diminished, substituted judgment is

required at that point which basically is the process of making the decision the incapacitated patient would have made based on their values if that person were decisional. However, the prerequisite for substituted judgment is that the patient needed to be decisional beforehand with previously expressed wishes.¹⁰⁷ This information can be made available in a living will or through an advocate with a durable power of attorney for health care. Failure to recognize or ensure this on the part of the medical professional would be unethical and would therefore violate the patient's autonomy.

The ethical dilemma that arises in the context of palliative care for patients that are terminal and particularly when death is imminent, is reconciling the right of the patient to refuse treatment, even if beneficial, with professional judgment. The converse is also true where the medical staff may perceive continuing treatment as maleficent but the patient/family wishes for the continuation of aggressive treatment. Situations such as the latter have often given rise to moral distress for medical personnel. Philosopher Andrew Jameton defines moral distress as "the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints."¹⁰⁸ Ulrich et al. suggest that in these moments interdisciplinary education and teamwork can contribute towards alleviating the duress.¹⁰⁹ These elements are of course what constitute palliative care.

Another important aspect in the area of patient autonomy and palliative care is the respect for human dignity, evident by the promotion of patient quality of life. At the foundation of the discussions on palliative or hospice care is the moral tenet of human dignity. As a patient's body is being decimated by disease this is a time when personal values are perhaps of greatest importance. In the midst of the suffering that can

accompany a malignancy a patient still wants to be respected and his or her human worth recognized. And so there is the idea of dying with dignity. Respecting a patient's right to accept or refuse treatment is also recognition of their human dignity as expressed through their autonomous decision-making. Despite the similarities of the dying process and the progression of disease among people, dying is still a unique and individual journey.¹¹⁰ However, Dula asserts that African-Americans view dignity in a different manner. Because of the history of assault on African-Americans through the medical and health care delivery systems it is not uncommon for African-Americans to view health care suspiciously. High mortality and morbidity rates along with shorter life spans give rise to this suspicion. Therefore dignity in the context of end of life care for African-Americans is more about quantity than quality of life.¹¹¹ More will be discussed on this later.

Autonomy does carry with it the burden of balance within the context of relationships and community. Janssens asserts we are foolish to make human rationality and autonomy so central in the healthcare paradigm because we are more interdependent than independent.¹¹² To assert absolute autonomy could give rise to a society of individual anarchy at the expense of community. Questions have been raised such as, "Is every individual's autonomy equal?" For the sake of society there needs to be a recognition that constraints are necessary with respect *to* autonomy, which leads to the following question, "To what extent should autonomy be respected?" These questions, Woods raises for consideration, especially within the context of healthcare.¹¹³ Woods further delineates autonomy into three areas: autonomy as defining personhood, an axiological view of autonomy, and the principle of autonomy.¹¹⁴ First he asserts, based on John Locke's philosophical view of self, that autonomy defines personhood through the

ability to think and reason. This particular link to personhood can be morally problematic for a patient in a persistent vegetative state (PVS) or another in the advanced stages of Alzheimer's. Secondly, the axiological view looks at the good life and the choices pursuant to it. How one person defines a good life may seem preposterous to another and according to Woods it also cannot be based on experiences. This then leads to the quizzical discovery of the variable meanings of "quality of life", a central concern of palliative care. Just as ambiguous as the definition of palliative care is, so also is the phrase "quality of life" and so applying the principle of beneficence has no standard of applicability but can differ from one patient to the next.¹¹⁵ Taking it one step further, when considering the purpose of palliative care, it is not the experiences of the patient alone that matter but what the family member(s) experiences as well. Robinson, et al., in analyzing 32 studies, report the experiences of patients and family members with palliative care in the hospital setting and note that most family members were dissatisfied with symptom and pain management and the busyness of the hospital environment leaving them feeling unvalued.¹¹⁶ For the efficaciousness of palliative care to be sustainable, personal autonomy must be revisited to where the issue of informed consent is broadened to include shared decision-making with the family. Massimo, et al. in considering consent from the discipline of pediatric oncology defines it as: "a shared cognitive process that needs a thorough awareness of the issues – not merely the state of being informed – by all parties involved."¹¹⁷ These issues should include emotional, psychosocial, as well as spiritual concerns. In the next section when physician responsibility is examined the issue of effective communications will be further explored.

However, effective communication skills are essential on the part of medical professionals in order for shared consent to be realized.¹¹⁸

Shared consent or shared decision making is not widely used.¹¹⁹ In some circles this is also referred to as negotiated consent.¹²⁰ But consent in the case of palliative care is not for medical interventions as in the case of curative treatments. It is to establish a plan of care. It is important to understand that shared, or negotiated decision-making is not a substitute for informed consent, it is informed consent. Whatever support system a patient utilizes to arrive at a decision for the type of care or treatment he or she wants needs to be recognized.

2.4.2 Physician Responsibility and Palliative Care

The Hippocratic Oath is one of the earliest texts that describe physician responsibilities. Even in this ancient treatise there is evidence of the obligation to hold patient matters in confidence, treat to the best of one's ability and refer when beneficial treatment is outside the bounds of one's expertise. As mentioned in the previous section, compassionately accompanying the patient and family members in the midst of their suffering is essential in palliative care. For Brennan, this connection with patients should exhibit poetic precision and detail, paying attention to the details of the physical symptoms of a patient, the "rhythm of their suffering" and their "season of grief."¹²¹ The amelioration of suffering – physical, emotional, spiritual and psychological is important in enhancing quality of life for patients with chronic and terminal illnesses. Because palliative care is a multidisciplinary approach to care, as highlighted in the Hippocratic oath, physicians need to be aware when it is in the best interest of the patient to consult with other members of the care team. Physically, how physicians manage patient pain is

essential. Prescribing an adequate dosage of analgesics can provide sufficient pain relief for the patient. Literature indicates that physicians are still under-treating pain for some patients. Scholars indicate that there is a risk of under-treatment for racial and ethnic minorities with chronic pain related to cancer¹²² and African-Americans in particular.¹²³ Michelle van Ryn and Jane Burke point out in their study that physicians rated African-American patients as less intelligent than white patients, even when patient sex, age, income and education are controlled.”¹²⁴ This perception could lead to the assumption that African-American patients are not able to understand treatment options which also encroaches on patient autonomy and borders on paternalism.

Communications between patient and physician is also important. For patients that are nearing end of life and for their families, communication is very important. Margaret Washington purports that doctors do not “hear” their patients. She reports that in a survey of over 2700 participants (1429 patients and 963 physicians) from across this country, 85% responded to the questionnaires examining patient-physician communications. Of the patient respondents 34% claimed that their doctors did not listen to them and 23% feel their doctors do not spend enough time with them. This compares to the 90% of the doctors who claimed they always listen. Of the physicians surveyed, 90% felt constrained by health care regulations. Particularly, limited formularies and prescription drug coverage, expensive co-payments, complicated referral systems, extensive paperwork all contribute to sub-optimal care physicians can give their patients and difficulties in communications.¹²⁵ Clearly, there is a disconnection. Under insurer driven managed care plans the time that physicians can spend with their patients is considered threatened as some plans incentivize physicians based on their reductions in

cost of care. Washington indicates this in itself places an additional burden on the communications between patient and physician¹²⁶ while Glasson, et al., point out that patient knowledge of this incentive driven care can impact the integrity of the patient-physician relationship.¹²⁷

Shared decision-making was briefly addressed in the previous section but this is critical for the healthy development of physician/patient relations. White, et al., identify the communications skills needed for physicians and illustrate a simple model for enhancing the dialogue with patients and fostering shared decision-making. The skills identified are *inquiry* and *informing*. The skill of inquiry “calls for an assessment of the patient’s current knowledge, expectations, preferred level of involvement, and preferred format or style for receiving and processing information.”¹²⁸ In making the effort to inquire with the patient, errors in judging patient perceptions or assumptions about a patient’s ability to process information can be avoided, a problem previously noted concerning African-American patients. Within the African-American community healthcare decision-making is a shared endeavor.¹²⁹

As previously mentioned, the guidelines offered by the National Consensus Project for Quality Palliative Care state medical professionals should regularly investigate the spiritual and existential concerns of the patient and family, provide and evaluate spiritual interventions that are culturally relevant and consistent with the faith tradition of the patient and family. The concern is, given the problems in patient-physician communications and the burdens imposed by managed care organizations, can physicians offer quality care, and especially give attention to something outside of their field of comfort – patient spirituality.

2.4.3 Justice and Palliative Care

Philosophers and theologians generally describe justice along the concepts of fairness, equity, and rights. In the area of health care it is distributive justice that most often qualifies the discourse. Distributive justice, according to Beauchamp and Childress is the “fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation.”¹³⁰ There are a number of justice theories that operate within the realm of distributive justice, namely, utilitarian, libertarian communitarian and egalitarian. The libertarian theory takes the position that health care is not a right and favors the position that what one receives, through insurance, is what one is able to pay.¹³¹ This position ignores existing inequities in health or health care and anything that may give rise to these inequities. This theory of justice would not be appealing to African-Americans and other disadvantaged groups, particularly Latinos, who find themselves in a social arrangement with the least social and financial capital and they both make up the larger percentage of people with chronic illnesses. There are some who argue that it is impossible to construct a health care system that offers the best care or equal care for all, due to limited resources or limited moral authority.^{132,133,134}

While not necessarily absolute equality, Veatch introduces the concept of essential equality on the argument that “there is something essential about humans independent of their social, economic, and intellectual condition.” He further asserts, due to the aforementioned, that health care systems should offer “the amount of health care needed to provide a level of health equal, insofar as possible, to other persons’ health.”¹³⁵ Veatch is known for promoting the egalitarian theory of justice for health care and refutes the notion that the egalitarian view operates from a psychology of envy. More

importantly he articulates that gross inequities are fundamentally wrong and that the disadvantaged are not in a position, due to unequal power, to represent their position with any sense of respect. Conversely those in power find it easy to conflate the argument of the disadvantaged with their welfare status thus making fair communications and a moral relationship impossible.¹³⁶

Earlier it was noted that there are some states that have hospitals with little to no palliative care programs. A discourse on the justice of this situation would wonder whether there is an obligation to expand the number of hospitals with palliative care programs and if so at what expense given limited resources. With the expanded definition for palliative care to encompass not only care at the end of life for patients who have terminal illness but also care for the chronically ill from the time of diagnosis, an additional burden is developed which further accentuates the broader ethical questions, how much and for whom? Daniel Wikler, in one of his works examining philosophical perspectives on health care access, notes although many philosophers would agree equality is too high an ideal, equitable access is more achievable. He continues by stating the consensus is loosely grounded in the dictum “treat equally unless there are morally relevant differences.”¹³⁷ As we will examine later, race and culture have certainly been the defining markers for health and health care inequities – undoubtedly immorally relevant differences. This is especially true among African-Americans. If palliative care aims to alleviate the physical, psycho-social and spiritual suffering of the chronically ill, and if a disproportionate amount of African-Americans fall into this category is there a moral obligation to shift attention and subsequently resources to address this disparity? Suppose we consider that many of the chronic conditions are due to environment factors

produced by social decisions. One might argue that this may be reason to push for some form of societal obligation. Engelhardt would first evaluate whether those in question are victimized by a natural or social lottery. If one is sick due to a genetic predisposition or “born unhealthy” this person has lost in the natural lottery and there remains proof of a secular moral obligation for society to bear the cost of restoration.¹³⁸

Norman Daniels in his book “Just Health” continues the premise put forth in his previous work, *Just Health Care*. Extrapolating Rawlsian just theory he builds on the question, “is health and health care of moral importance?”¹³⁹ In an admission of shortsightedness Daniels takes the opportunity to correct his original position that a just theory for health can be realized through a just distribution of health care. What he later explicates is that in order to realize justice in health, which includes health care, you have to factor in the other social determinants of health. This expands the discussion on just health care to justice in population health. However, when we discuss anything pertaining to a population, justice begs us to ask whether or not there is a public responsibility in creating and maintaining population justice. So, in “Just Health” Daniels takes his original foundational question mentioned above and divides it into three, specifically:

1. Is health, and therefore health care and other factors that affect health, of special moral importance?
2. When are health inequalities unjust?
3. How can we meet health needs fairly under resource constraints?¹⁴⁰

Daniels, in developing his theory of justice for health and health care borrows from Rawls the foundational notion that health and health care are “goods.” However he departs from Rawls’ distinction that health is a “natural good” while health care is a “social good” because of his evolved understanding that there are a number of social determinants to health that leads to inequities in the distribution of health care as well and

consequently disparities in health.¹⁴¹ For Daniels, as well as Rawls, health is essential to “normal functioning” which can then lead to equal access to opportunities and allow people to participate as free and equal citizens in society.¹⁴²

Lisa Cahill, in her work “Theological Bioethics” addresses national and international health access reform. Like Daniels she borrows from a Rawlsian theory of justice and looks at health care as an essential common good. Cahill qualifies the issue of public responsibility for access to health by pointing out the need for a theological response from a variety of religious groups and respected theologians and not just verbally but also in a form of activism if necessary¹⁴³ Cahill further defines health as “a person’s ability to function in his or her social and physical environment.”¹⁴⁴ The issue of access to health care is replete with contributions from philosophers so Cahill is right in soliciting scholastic contributions from theologians. However, one problem with Cahill’s definition is the reality that some social and physical environments are subpar in comparison to others. One would wonder if a patient would be considered in good health if that person is able to function in an impoverished community with limited access to a hospital or even a grocery store, not because the rehabilitated patient is immobile but because neither the store or the hospital exist in the community. This is certainly a reality in many neighborhoods and communities across this country. These theories will be further developed in the chapter that considers race and healthcare.

With the ongoing debate surrounding what constitutes adequate access to health care one has to continue to wonder what this means for access to palliative care, especially among a population of people that have historically been disadvantaged, namely African-Americans.

2.5 Palliative Care and the African-American Perspective of Medical Ethics

As we investigate the values and benefits of palliative care for African-Americans it is necessary to first examine medical ethics from an African-American perspective. In order to facilitate such an examination it is most important to acknowledge race and racism, their factors in the health outcomes of African-Americans and their marginalization and/or suspension within bioethical discourse. According to Dula, there has been very little research and discussion around the issue of race and racism within the field of bioethics.¹⁴⁵ She further asserts that this is partially due to the lack of diversity, and specifically the dearth of African-American scholars, in the field of bioethics.¹⁴⁶ It must not be underestimated that some parallel racial difference with intellectual deficiencies. According to philosopher Bernard Williams, it is an irrational state of affairs when it is conjectured without evidence that race-based intellectual differentials warrant unequal treatment.¹⁴⁷ Karsjens and Johnson highlight what they call “white normativity” in the field of bioethics and within supporting institutions. They state, “the discussion of white normativity, encompassing both white dominance and privilege in the field of bioethics requires a critical analysis of the inextricable relationship between the sociological construction of race, the role of cultural capital, and the development and schematization of white hegemonic structures.”¹⁴⁸

There are challenges when considering offering palliative care services to African-Americans over and against other populations. Some of the challenges are on the part of physicians. A UCLA study suggests that white physicians are more likely to prescribe lifesaving HIV medications to white patients more frequently than they are to African-American patients.¹⁴⁹ Karsjens and Johnson, in referencing Noah’s evaluation of

extended wait times for African-American organ recipients state, medical professionals make racially based decisions when evaluating and ranking recipients for eligibility.¹⁵⁰

Continuing the discussion on palliative care for African-Americans it should be concluded that this can best be done by recognizing medical ethics as informed by the experiences of African-Americans from the existence and magnitude of health and healthcare inequities and the complicity of institutions, members included, in the perpetuation of mistrust from this community. To properly attend to the needs of African-American patients one must be aware of some of their cultural idiosyncrasies. One may wonder if it is possible to pay special attention to a particular population when offering care while simultaneously universalizing a consistent approach to care. In identifying the particularities of African-Americans, Garcia¹⁵¹ suggests an African-American medical ethics perspective that includes the following: (a) anti-majoritarian and anti-utilitarian, (b) anti-situationist, (c) distrustful of an ethics of trust, (d) sympathetic towards families, (e) open to regard the patient as the one with the decision to make, and (f) open to the insights from religious faith. A careful look at this list of suggestions offers a similarity with the established palliative care framework, specifically, the attunement to spiritual needs, attention to the needs of the patient as well as the family. Over and above this is the mandate to not insist that trust is pre-established between patient and physician, that medical professionals representing the dominant culture recognize their inherent dominance and that African-American patients are able to make informed decisions. A somewhat similar balancing act is taking place with the European Association of Palliative Care. In an effort to build consensus around the delivery of palliative care in European countries the European Association of Palliative Care (EAPC) recognizes the

challenge amid the varied European cultures represented by the association.¹⁵² Based on these efforts one would think it not only possible but fair, when looking through a lens of justice, to establish a model for delivering palliative care services to African-Americans even though, according to Garcia it is “socially dubious to think there is one culture shared by all African-Americans.”¹⁵³

Reginald Peniston offers another quasi-countervailing position. Peniston asserts that putting forth medical ethics from the perspective of African-Americans is in itself dubious much like many African-Americans would not expect General Colin Powell or former Secretary of State Condoleezza Rice to be their spokespersons. His point is that there is a myriad of thought and experience as well as a divergence of opinions within the African-American community that would make such a claim on an African-American perspective on medical ethics suspect.¹⁵⁴ He further states, from his experience as an African-American physician, that he sees no evidence that an African-American ethical perspective would alter bedside decision making by a physician.¹⁵⁵ On this point it would be helpful for Peniston to consider revisiting his perspective from the perspective of patients and not a physician. While Peniston’s point has merit in the confines of opinions on narrow issues, the plethora of evidence and the broad experiences of African-Americans in this socio-political hemisphere are replete enough to render his position against the development of African-American perspectives in medical ethics as hyperbole. There will be more information presented later that further build the case for balancing the treatment of African-Americans when the chronology of historical mistreatments alongside contemporary research survey results are shared.

While it may not be feasible to develop an ethics of palliative care for African-Americans alone, it is ethically expedient that attention must make room for the reality of mistrust of healthcare from this patient population. This subject will be discussed further in the chapter discussion on race and healthcare.

2.6 Palliative Care Program Development among African-American Populations

There have been various institutions that have modeled how to operationally deliver palliative care services to African-Americans and other populations that have traditionally had minimal access to quality healthcare. Three of those examples are the Harlem Palliative Care Network, Hospice of the Valley in Santa Clara County and the Balm in Gilead Project at Cooper Green Hospital in Birmingham, Alabama. The Harlem Palliative Care Network was a collaborative project between North General Hospital in Harlem, Memorial Sloan-Kettering Cancer Center and the Visiting Nurse Service of New York.^{156,157} While most of the patients seen in this program were cancer patients, its target population is patients with HIV/AIDs, end-stage renal disease (ESRD) and chronic obstructive pulmonary disease (COPD). Some of their success can be attributed to the identification and inclusion of community stakeholders on an advisory board, offering palliative care training to North General Hospital medical professionals and establishing relationships with community clergy. The Balm in Gilead Project had similar success before closing in 2013 utilizing similar networking strategies. Through its “Caresharing Initiative” volunteers were mobilized through two programs, the CareTeam Program and the Adopt-a-Room Program. In the palliative care unit of Cooper Green Hospital patients were cared for in rooms furnished by local churches and community groups. At Hospice

of the Valley, improving the cultural competency of the hospice staff was important and so a handbook was created for the use of all hospice workers. Later, this dissertation will address the inadequacy of cultural competency in providing care for African-American patients.

2.7 Palliative Care and other Ethical Challenges

Palliative care was at one time primarily focused on patients with advanced stages of cancer. But as time has progressed the scope of palliative care has broadened and is no longer limited to cancer patients and no longer limited to diseases advanced to terminal status.¹⁵⁸ In the midst of ambiguity with respect to terminology and practice, palliative care must now be offered to patients in more varied disease states and with this an ethic untethered from medical ethics. For example, one of the bigger challenges is the care for patients suffering from dementia and Alzheimer's disease. In this case, as mentioned previously, the patient's ability to rationalize diminishes as the disease progresses and decision-making takes on a different complexity. Also one of the goals of palliative care is to "lessen pain and other burdensome symptoms " and "help patients become as active and autonomous as possible"¹⁵⁹ which is a dissonant for the care of patients with dementia and Alzheimer's. How palliative care is viewed in such cases is quite inconsistent in countries on the other side of the Atlantic. For example Rikkert reports that in Dutch hospitals a patient with Alzheimer's will receive palliative care if there is a co-morbidity and the condition is terminal.¹⁶⁰ And what would be considered symptomatic care in the Netherlands is just a narrower application of palliative care in the U.S and other places.¹⁶¹ The field of geriatrics has been able to become an established discipline in caring for the elderly and palliative care is becoming established as well in

establishing protocols for caring for those for whom death is imminent and those with a terminal illness. But according to Boitte for patients with dementia and Alzheimer's the intersection of these two disciplines is slow in developing.¹⁶² With respect to interpersonal relationships and the importance of communicating, something important in palliative care, when the patient is unable to communicate effectively due to cognitive declination and when the family is under duress and distress because of the visible decline, the need to provide psychosocial and spiritual support is ever present. When the patient appears to be a shell of who he or she once was there is still the need to promote the utmost dignity for the patient. Lastly, in the mitigation of suffering, how suffering is defined for this patient population, especially the Alzheimer's patient becomes complex which leaves the application of palliative care suspended.

In the U.S. very few dementia patients are admitted to hospice and therefore may not receive the best care possible and those in hospice for whom the primary diagnosis is dementia represent a very small percentage.¹⁶³ For African-American patient population for whom hospice is under-referred this could present a serious problem for the patient and their family. One program that appears to be leading the way in offering quality care to patients with dementia and Alzheimer's is the Palliative Excellence in Alzheimer's Care Effort program created through a collaboration between the University of Chicago and Hospice of Michigan. This program integrates palliative care into the primary care for patients with dementia and provides the care throughout the disease trajectory and also offers "hospice-like" care to the patients in advanced stages of dementia before their Medicare eligibility.¹⁶⁴

2.7.1 Terminal Sedation and Palliative Care

Another area that has created an ethical dilemma in the area of palliative care is terminal sedation. Scholars argue that there is a fine line between sedating for refractory pain that is physical in nature versus psychological.¹⁶⁵ One article points out that the term itself has been controversial and upon the suggestion of a group of palliative care experts that another term be used in its place.¹⁶⁶ For African-American patients who already negatively view hospice as “giving up” using a term like terminal sedation in the process of communicating treatment options could prove problematic. In addition to being controversial Broeckaert, et al. suggests that the term “terminal sedation” also does not explicate what the course of treatment entails and is also easily confused with euthanasia. They further mention that other alternative attempts at replacing the term such as “sedation for intractable distress in the dying” and “sedation in the imminently dying patient” are equally unhelpful. Instead they offer the term “palliative sedation” as a qualified substitute.¹⁶⁷ While euthanasia and physician-assisted-suicide are legal in the Netherlands, in many other regions around the globe they are not.^{168,169} Therefore, any perception that a form of sedation is shortening life is ethically problematic for many and it is good to be clear about defining symptom and pain management. For Broeckbaert, et al., proportionality in analgesic administration is critical in distinguishing between involuntary euthanasia and palliative sedation.¹⁷⁰ The EAPC Ethics Task Force requires that for patients for whom death is imminent, palliative sedation and euthanasia must be clearly distinguished.¹⁷¹

2.8 Conclusion

The movement of palliative care is gaining momentum in the U.S. and around the world. From its antecedent work of hospice care, a specialized form of care for the terminally ill developed in Great Britain by Cicely Saunders, palliative care was primarily a service offered by nurses and focused mainly in the area of oncology to alleviate pain and suffering for patients near the end of life. It has been argued how the deficits in-patient care for African-Americans, and their use of spirituality to cope with illness and to carry themselves through their distrust of the healthcare system must be recognized in providing quality palliative care. The positive effects in healthcare outcomes from the use of spirituality was expressed in addition to how spirituality has been a core component of palliative care in theory but still largely ignored in practice.

The rights of people to have access to quality palliative care, especially African-Americans, was examined as well as how the current inconsistent delivery of palliative care could create disadvantages for patients. The fact that there seems to be a pattern that the fewest number of hospitals with palliative care programs coincide with states with the highest population of African-Americans leaves some concern. It was also conveyed how healthcare disparities in addition to the failure of fully identifying, addressing and alleviating the suffering of patients, through the inability to provide holistic care, is a social problem.

How palliative care is received or not received among African-American patients and families is affected by the need to be aware of an African-American perspective of bioethics. In addition, African-Americans are less likely to share their medical preferences in writing. There are a number of factors considered as reasons why this is

the case such as a lack of awareness or understanding of the importance of advance care planning, mistrust in the health care system, religious and cultural beliefs. In addressing the lack of awareness or understanding some of this points to preconceived perceptions of African-American patients and or cultural insensitivity or incompetence on the part of medical professionals. Scholars also point out that African-American patients were considered less intelligent by physicians than white patients, even when controlling variables such as patient sex, age, income and education. This among other things is reason for the huge and consistent disparity in care for African-American patients.

Future developments in palliative care ethics will have to consider how to separate from a medical ethics paradigm and into an ethical identity of its own and in doing so, consider how this ethic can be applied to provide optimal care for patients suffering from diseases like Alzheimer's and dementia. Within the medical ethics paradigm patient autonomy is carefully respected and has been in response to what was considered a paternalistic disposition of physicians toward patients. However, over the course of the disease progression communications with patients challenged by these diseases becomes challenging both for the medical professional as well as for family members. Suffering for these patients takes on a different meaning, especially for Alzheimer's patients, as they are not able to share this effectively. As reported, Alzheimer and dementia patients are referred to hospice at a lesser rate than patients with other maladies. It will be of special interest to see how African-American Alzheimer and dementia patients fair given the recognized barriers to hospice care already affirmed.

Terminal sedation creates another ethical challenge both in the terminology used as well as the myriad views and opinions regarding the proper administration of opiates

and analgesics for terminal patients for whom death is either imminent, pain is refractory or both. In addition, the challenge can be exacerbated as the issue of euthanasia and physician assisted suicide gains positive acceptance in the U.S. and abroad.

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Chapter 3. African-Americans, Race and Health Care

3.1 The Historical Development of Race and Racism

Palliative care extends the traditional care model by addressing other dimensions of patient suffering besides the physical, including the spiritual and psychological. To provide effective palliative care to African-Americans it is important to contextualize their suffering beyond their medical anomalies. African-Americans have had the longest and most challenging history of any ethnic group in this country and it has been anchored in negative perceptions of race. Before attempting to outline how the health and wellbeing of African-Americans were diminished by discriminatory practices based on race it is important to begin with an analysis of the origins of the concept of race and its pejorative applications. To that end, it is important to, in as brief yet succinct a manner as possible, trace the origins of the term “race” and the subsequent influences and eventual mistreatment of African-Americans. In doing so one will see how “race” has been engrained throughout the various domains in society in the U.S., especially in healthcare. Winthrop Jordan states that racial attitudes are very different now than they were in the past and therefore the concept of race needs to be contextualized.¹ This is the respectful application of hermeneutics, a tool used within the wide discipline of historical analysis. While I agree with this point it will be the purpose of this chapter to reveal that despite the passage of time and the development of new understandings, there has not been an evolution of racial attitudes as much as there has been a mutation. While these two terms may and can be used interchangeably, evolution connotes a constructive development leading to positive outcomes in general. So, over the course of time, technology and the

use of technology has evolved in such a way to enhance life, community development, society and business. Cellular organisms forming viruses and other diseases mutate in response to changing environments in order to maintain their chronic or acute natures thereby negatively affecting human life directly and community life indirectly.

Slavery in America was the antecedent to the myriad forms of mistreatment of African-Americans and so while this chapter begins by mining the term “race” as a mineral of human sin, it is equally important to look at how race was used in the development of a system of enslavement in this country with the African-American as the sub-human object. This is where there will be a shift from examining race to examining racism. While slavery was the system, it needed racism as its lifeblood in order to continue to function. When this system was threatened, this lifeblood of slavery, needed to find another route and system from which to function. That system would be called “Jim Crow.” All of this had an effect on the health of African-Americans and even with the development of a care delivery system also known as health care racism found its resting place and over the years further impacted the health of African-Americans. However, to move to an examination of health disparities between African-Americans and Whites in this country without doing so from a longitudinal analysis would be a form of malpractice in its own right.

In this chapter, the term “African-American” will be used preferably. Where appropriate the terms “Black” or “Negro” will be used.

3.1.1 “Race,” Its Etymology and Evolution

The terms racism, race or racists did not garner their current meanings until the turn of the 20th century.² But what will be examined here is the longitudinal history of the

latitudinal influence that gave rise to what African-Americans have experienced over four centuries in America. Here in the 21st century, the terms race and racism are politically charged terms, terms that invoke a sensitive navigation in conversation otherwise known as political correctness. There is a substantial amount of scholarship that exists, produced by historians, anthropologists, anatomists and philosophers on the categorizing of the human race. Taxonomy and physiognomy were the branches of science that became the playground for means of categorization. The European Renaissance along with the Age of Enlightenment, which together spanned 6 centuries, were periods of significant influence in art, literature and science and eventually on social thought. It was during this period that certain ethnographic terms began to take on divergent meanings. According to Nicholas Hudson, “race” and “nation” were linked to the connotation of lineage or stock. “Tribe” began to be used in place of “nation” to pejoratively describe non-European “savages;” “nation” was used to describe European social and political divisions, and “race” became the dominant ethnographic descriptive medium.³ Hudson bookmarks the tangential use of the term race as a personal descriptor to the 18th century.⁴

Galen, the Roman physician (around AD 160) described the genitalia of African men as oversized and their intellect inferior.⁵ Claudius Ptolemy, a 4th century mathematician, astronomer, philosopher and student of Aristotle, proffered that the darkness of the “Negro” and the texture of their hair was due to the heat of the sun.⁶ During the Medieval period, which preceded the Renaissance period, people were defined according to their temperament and character in addition to physiognomy. At the time it was believed that these different characteristics were due to geography and climate.⁷ English explorers during the 16th century, traveling to West Africa to trade

referred to the African men as “brutish” and “beastly.”⁸ Earlier historical accounts of travels to the regions in Africa were inconsistently favorable or unfavorable. John Ogilby, a 17th century cartographer, noted that the inhabitants of southern and west central Africa were “scarcely above Beasts” while his view of the Abyssinians were “quick spirited, and lovers of learning and learned men while their women diligent and zealous of literature.”⁹ The Abyssinians were in Northeastern Africa in the region now known as Ethiopia. But later in the 17th century it became apparent that Europeans would view themselves as more superior to everyone they encountered. This differential was not based on race but based on what they considered sophisticated and civilized.¹⁰

As the 18th century began to mark its claim on history a preoccupation with “race” developed where many scholars during this period began to view Africans as biologically inferior. This development is believed by some to have been established to justify what would become the slave trade to the Americas.¹¹ This perspective of inferiority allowed the slave trade to ignore temperamental variants of the Africans across the different African nations and scoop them in the dragnet of slavery. According to Hudson, “slavery subjected Africans of diverse cultures, languages and levels of ‘civilization’ to a uniform system of debasement.”¹² The injection of science as a legitimizing agent promoting racial hierarchies provided the sound foundation for the objectifying and classifying of Africans and fueling a system that thrived on the prescribed inferiority of Africans.¹³ The degenerative use of the race seemed to gain influence through the works of Georges-Louis Leclerc, Comte de Buffon, the 18th century French naturalist. Buffon was the first to use the term race to designate previously identified human subgroups – Europeans, Asians, Americans and Africans. Despite inexact science and inconsistent use of the

term, Leclerc proposed that race was rooted in climate and geographic variations, as was previously ascribed.¹⁴ If inhabitants of two different countries share the same geographical latitudes yet are dissimilar in color it is due to the fact that the more fairer of the two is more “polished”, “live in towns”, and “practice every art to guard themselves against the injuries of the weather.”¹⁵ Leclerc also comments on behavior. In his reflection concerning the inhabitants of Brazil, Leclerc noted the difference in behavior between those living on the coast and those living in the interior of the country. He states that the coastal inhabitants are more civilized because of their interactions with the Portuguese in trade while those living in the interior exhibit savagery. However, the savages who became amenable and civilized were influenced by the work of missionaries and not through military force.¹⁶ This particular link between the work of European missionaries and the behavioral conversion of people would figure significantly in the African slaves transported and traded in America – the progenitors of African-Americans. Leclerc joined others in his time in hypothesizing that the blackness of the African was due to the color of their bile and blood.¹⁷ Leclerc’s works influenced German physician, naturalist and anthropologist, Johann Friederich Blumenbach who was considered the father of physical anthropology.¹⁸ Blumenbach wrote a piece on the “degeneration” of races. His theory is based on the premise that all humanity is of one species and each race is a subsequent degeneration from his ideal race, which is Caucasian because they exhibit the “most beautiful race of men.” The Ethiopian, however, is the furthest away from this perfect ideal at one extreme with the Mongolians at the opposite extremity, these two being so starkly different from each other while degenerate from the Caucasian race.¹⁹

The propositions on the constructs of race were not limited to the scholarship of naturalists and anthropologists. The schools of philosophy also offered their share of opinions. David Hume, the noted 18th century philosopher purported that all human species or races are inferior to the White race and that “there never was a civilized nation of any other complexion than white.” He further remarks that with the dispersion of slaves throughout Europe none of them “discovered any symptoms of ingenuity; though low people without education will start up amongst us and distinguish themselves in every profession.”²⁰ Hume’s claim is that these characteristics are a product of nature. Scottish philosopher and poet, James Beattie did not embrace Hume’s views and published in his work “An Essay on the Nature and Immutability of Truth, in Opposition to Sophistry and Skepticism” a contrary position. Beattie noted, “The Africans and Americans are known to have many ingenious manufactures and arts among them, which even Europeans would find it no easy matter to imitate.” Also despite the unhappy conditions of the dispersed slaves in Europe they have been able to “discover symptoms of ingenuity.”²¹ Immanuel Kant, a contemporary of Hume, and the one credited in the world of philosophical ethics with the categorical imperative, foundational in deontological ethics offered a similar pejorative narrative of the Negroes in Africa. Kant states, “The Negroes of Africa have by nature no feeling that rises above the trifling.” He further asserts that the difference between Whites and the African Negro is as great in “mental capacities as in color.”²² Kant’s views were also sharp toward African religion when he described African worship as idolatrous and trifling making reference to their use of bird feathers, conch shells, cow horns and other objects.²³ It is this type of thinking that gave rise to the misunderstanding that missionaries converted African slaves to

Christianity. This point will be developed further in a subsequent chapter. But just as Hume had his critics so also did Kant. J. G. von Herder actually offered a response to a critique Kant made of his essay, “Ideas on the Philosophy of the History of Mankind.” Herder did not approve of Kant’s view that mankind should be divided by race based on the color of their skin²⁴ and that it is “just, when we proceed to the country of the blacks, that we lay aside our proud prejudices, and consider the organization of this quarter of the globe with as much impartiality, as if there were no other.”²⁵

In the halls of academia the works of Hume and Kant are highlighted as cornerstones of excellence in critical thinking and deserved so to a point. But how can you separate the scholarship from the character? The pronounced prejudice of both men is rarely discussed in the context of ethical theory. But it served as an undercurrent to their personal identities and when contextualized alongside their ethical theory taints the efficacy of their work. Perhaps this is why this character flaw of either man has been a silent partner in ethical discourse. One has to hunt for the contrarian views of James Beattie and J. G. von Herder because the superiority posture of Hume and Kant is not in the forefront.

In the 20th and 21st centuries Hume, Kant and all who shared their views would be considered racists and the ideology fueling the thoughts and actions would be considered racism. Some scholars like Benjamin Isaac and Barbara Jean Fields consider racism an ideology.^{26,27} Fields further defines an ideology as “the language of consciousness that suits the way in which people deal with their fellows.”²⁸ Isaac also defines racism and distinguishes it from what some would call ethnic prejudice. The distinction Isaac makes is that “ethnic and religious prejudice leaves its victims with the presumption of choice or

change, while racism does not.”²⁹ In other words because of the structure(s) that give way to racism those victimized by it have no choice but to live within this structure. Rather than presume these pejorative ideas suddenly materialized during the European Renaissance and Enlightenment periods, he traces the ideology back to Antiquity, to the Greco-Roman era. However, as an act of academic accommodation, Isaac reaches back to antiquity and rather than describe the structure as racism, he instead terms it “proto-racism,” not to insinuate that it was a weaker version but just that it was a pre-mutated version in a different cultural context³⁰, or as David Goldberg states, “patterns of ‘hostile thinking.’”³¹ For example, the Athenians had a strong position on the purity of their lineage.³² This thinking was no different than undergirded Hitler’s extermination of the Jews as well as modern day Aryanism. Goldenberg remarks that there was no hiding the Greco-Roman distaste toward Africans (Ethiopians).³³ In referencing another source, Goldenberg asserts that Benjamin Franklin embraced a land of only White people. He quotes, “Why should we...darken its people?” Why increase the sons of Africa by planting them in America, where we have so fair an opportunity by excluding all blacks and tawneys.”³⁴ What Isaac notes in regards to the Greco-Roman culture are three important ideas that helped scaffold a proto-racist ideology and they are: environmental determinism, inheritability of character, and the importance of lineage.³⁵ Environmental determinism was the antecedent to the 17th and 18th century climate-based race characterizations mentioned earlier. But if the Greco-Roman era wasn’t early enough, Isaac links environmental determinism to the 4th century BC with Aristotle’s commentary in his work *Politics*.³⁶ In addition, through extensive research Isaac pinpoints the

beginnings of the “essence” of racism to this Hellenistic period, including plans for Jewish extermination.³⁷

What is just as important is how the “essence” of racism was integrated into religious thought and practice. This happened through color symbolism and allegorical references. Black and white became associated with evil and good, death and life, respectively, despite the fact that the Hebrews associated the color red with sin in their sacred texts.³⁸ In 16th century England black and white symbolized filth and purity, ugliness and beauty, the Devil and God, respectively.³⁹ Biblical exegesis is the art of interpretation and critical explanation by looking at the original languages of scripture. Philo, a respected Hellenistic-Jewish philosopher from the 1st century incarnated evil by associating it with the Ethiopians although there is no association of the sort, explicit or implicit. Others did likewise whether in the rabbinic tradition or church fathers, also known as the Patristics.⁴⁰ Two such examples are Origen and Irenaeus, 2nd century theologians. Both of them used poetic license to take scriptures that refer to darkness and make reference to Ethiopians thus expanding negative connotations towards Ethiopians or Africans.⁴¹ There, then, could be absolutely no way that a Christ figure could have any resemblance to the Ethiopians; if anything, the complete opposite. So as Joseph Ziegler notes, in the area of physiognomy, 13th century Latin texts, distributed widely identify Jesus Christ as a well-tempered person who would mostly likely have the mixture of white and red color in accordance with physician Michelle Savonarola described as an ideal person.⁴² There were some who looked at the color of Africans as a curse from God. Referencing the Genesis 9 text where God cursed Ham, the son of Noah, Canaan and all of his descendants, Europeans saw this as a way to justify an alternative natural negative

view of the skin color of the Africans.⁴³ This ancient thinking was able to transcend time to where even White supremacists in America have used this information as a platform for their targeted hatred of African-Americans. Robert Bennett Jr. suggests that a whole, “deep seated modern racist attitudes have built a theology built on African inferiority and have caused the thinking of many that Egypt is somehow separated from Africa and that any African culture is of Egyptian origin.”⁴⁴ Bennett criticizes the work of Charles Gabriel Seligman for projecting such a dissection of the continent. Bennett states that Seligman could, “speak of the Egyptians as Caucasian Hamites (descendents of Ham) who were superior mentally and otherwise to the dull and darker African Negro.”⁴⁵

In conclusion, from the linear development of such prejudice towards Africans over the centuries it was practically natural to subjugate and oppress the Africans and eventually segue to what would be known as the Slave Trade and eventual mistreatment of Africans who would later become African-Americans. According to Lerone Bennett, “the slave trade was a black man who stepped out of his hut for a breath of fresh air and ended up, ten months later, in Georgia with bruises on his back and a brand on his chest.”⁴⁶

3.2 History of Mistreatment of African-Americans

Slavery was practiced in many forms over the centuries. The Bible records that the Israelites were slaves under Egyptian rule for over four hundred years. Enslavement was common in those days and who became slaves was randomly white, brown and black men throughout the ancient world. Lerone Bennett states that slavery in the ancient world was different than modern slavery in that during the former times slavery was not based on race but was part of the rules of war.⁴⁷ Christians enslaved Muslims and Muslims

enslaved Christians. Moors were captured in North Africa and were enslaved in Italy. It was Portugal that led the way to transatlantic slavery in the 15th century taking slaves back to Portugal. Over a ten-year period it is recorded that Portugal extracted on average one thousand Africans per year resulting in some areas in the country where African immigrants outnumbered the Portuguese.⁴⁸ However, the way African immigrants were treated in Portugal was very different than the way those eventually transported to America would be treated. The intermingling of Africans and Portuguese became common.⁴⁹ It is reported that many Africans accompanied the Portuguese and Spanish explorers on their transatlantic voyages. One in particular, Estavanico, piloted his own vessel and established the areas of New Mexico and Arizona for Spain, and Pedro Alonso Niño piloted one of Christopher Columbus' ships.⁵⁰

As depicted in the previous section, the mistreatment of African-Americans has a shadow that traces back for centuries through their ancestral lines to the continent of Africa at the hands of Europeans. In this section we will explore the history of turbulence in the U.S. While the history shared will not be completely comprehensive, it will show the patterns of actions intended to build lasting systems to continue to oppress African-Americans and suppress their advancement. This section will examine the life of the African-American in general during antebellum slavery, Reconstruction and Jim Crow in addition to occasional reference to contemporary markers. The next section will examine the challenges of healthcare interwoven in that life.

Slavery in this country is one of the most significant blemishes in this country's history. It is extremely important to understand the environment African-Americans were

subjected to in this country from the period of antebellum slavery through Reconstruction, Jim Crow and up to and including the present.

3.2.1 Slavery – the Beginning of American Dehumanization

The whole notion of using Africans as slaves was started by the Portuguese and Spaniards during religious wars against Moors. The Portuguese in their travels down the coast of Africa would transport Africans back to Portugal. Thousands were taken before the year 1500 and used as slaves. After the year 1500 Portugal and Spain had developed a lucrative system of delivering slaves to the Americas.⁵¹ The earlier settlements were in the West Indies or Caribbean and it is believed that the use of slaves in the Americas began here on the Leeward Islands, with Barbados as one of the major ones.⁵² And so, slavery was established in the New World. This development was not obscure to the English although for much of the early development of the slave trade they were not participants. England from the 1500-1700s was an interesting time period for examination. The reason why this is important is because of the eventual English settlements in America. The Englishmen would bring with them certain thoughts and ideas, thoughts and ideas that would be used to replicate life experienced in England or to create a new life altogether. According to Jordan, before this time, the color of the “Negro” was not a preoccupation though an obvious distinction.⁵³ English life was a life of piety where Scripture was an important source of spiritual reflection and self-examination.⁵⁴ This point is of noted significance. Those who settled in the New England area were primarily Puritans compared to those who settled in the southern colonies. As previously mentioned there were some Europeans who, through Scriptural interpretation, viewed the Negro as a people cursed by God and their skin color served as the evidence.

This began to show up also in England as well. Some of this can be traced to Elizabethan scientist and explorer, George Best. Best purported that Noah, his sons and wives were white and therefore the descendants should also be white. However, because of Ham's disobedience, under the influence of the Devil, God "willed" that he would have a son named Cush in which he and all of his descendants would be "black and loathsome" and that this would be a sign of disobedience for the entire world.⁵⁵ What order did Ham disobey? Ham disobeyed Noah's order to have intercourse with their wives while on the Ark during the flood. As conveyed in the previous sections on the development of race and the characterizations of the African, the process of association can result in the linkage that the libidinous nature of Africans is linked to the sexual sin of Ham. In addition, one can also see a linkage between the Devil and sin with blackness as a consequence. So, there is the obvious subsequent association of white with good and God, and black with the Devil and evil.

It is important to note that within the European lexicon there was a distinction between servants and slaves. Indentured servitude was not uncommon, particularly in England. The key to servitude was its term limits. Personal freedom was an important virtue in England especially at the start of the 16th century. But slavery was not outside of their purview. A slave was not only to serve but was to serve for life and that condition, was perpetual, conceptually, if not yet in practice.⁵⁶ Because of the heavily Protestant influence in the country, slavery and its accompanying essence was antithetical to Christian beliefs. It was not right for a Christian to hold another Christian in bondage or service forever; this was reserved only for beasts.⁵⁷ But as was previously mentioned, in 16th century Europe the thought that Africans were beastly was ubiquitous and it was not

unlikely that this thinking crossed the English Channel. Furthermore, this pious disposition of relational respect was between Christians. Africans in the minds of the explorers, English and non-English, were savages. Therefore, when the English were made aware of the slave trade operations from Africa to the West Indies by the Portuguese and Spaniards their actions were not heathenness to them. In what would become a token of unpleasant irony, an 18th century Christian English sailor would be instrumental in carrying African slaves from Africa to America. The irony is not in that he was an English sailor, or that he was Christian. This sailor would be famous for penning some of the more prominent hymns used in the Christian church. His name was John Newton and his most famous hymn was Amazing Grace. It was not antithetical to have a strong faith in God on the top deck of a ship while the cargo you carried below were Africans ready to be sold into slavery.⁵⁸ This twisted form of religious piety would later become pervasive in the English colonies and the eventual United States of America.

England at this time was also in the midst of economic transition. 16th century England is considered to be the transition point between Medieval and Modern periods of political and economic development.⁵⁹ England was still very much an agrarian society with competition for the use of land between crops, sheep and cattle.⁶⁰ There was a demand for sheep because of the need for woolen exports to meet the growing demand of imported exotic foods, wines and furs for the social elite.⁶¹ However, there was also widespread poverty in England. The challenge of producing enough crops for food was also met by the challenge of the ability of people to purchase the food. For those farmers who were unable to sustain their livelihood migrating to the towns from the countryside

was the only option. There the shortage of labor was not the issue but conversely an overabundance of labor. So it was not uncommon for vagrancy and begging to be the saturated norm saturating the urban centers.⁶² Famine and pestilence permeated England, shortening the lifespan of many.⁶³ With these conditions, famine, pestilence, land shortage, crowded cities, finding a new frontier made much sense. So, the explorers looked for a new world and found it in the Americas.

The experience on the continent of Africa during this extraction was not so pleasant. Africans were caravanned, through the hills and flats toward the coasts of West Africa. Many could not make the journey and died along the way either by throat slashing or just left to be eaten by the wild animals if they fell ill.⁶⁴ They traveled upwards of 500 miles on foot.⁶⁵ On the ships during the transatlantic trip known as the Middle Passage, the slaves, men and women were compressed into the lower compartment of the ship, body against body so much so that the slaves were not even able to turn around. For this voyage, which lasted approximately 6-10 weeks slaves would suffocate to death or go mad in the process. To make room it was not uncommon for a slave to kill the person next to them either by strangulation or driving a nail in the person's brain.⁶⁶

In the West Indies the overcrowding of Europeans gave way to influx of African slaves as free labor to work the sugar plantations as the Europeans migrated to the English colonies and to the larger island of Jamaica. They were enslaved there for life along with the Indians.⁶⁷ The enslavement of Africans in the West Indies was influential in the New England area, ironically. It was ironic because there were no plantations in New England and no staple crops to farm, therefore, no economic justification. It is believed that those who brought the Africans from the island colonies to the New

England area and sold them, did so with the notion of keeping the slaves under perpetual servitude rather than providing any hope of liberation and shifting their status to indentured servitude.⁶⁸ Things were developmentally different in the Maryland and Virginia areas during this time. One reason for this difference was the need for cheap labor to work the tobacco farms. In the West Indies it was sugar.⁶⁹ Contrary to the conditions back in England, there was no shortage of labor or land. But there were other Englishmen in addition to Indians who were available for service. In early 17th century Virginia, much of the work in the tobacco fields was performed by English indentured servants. It wasn't until later in the century that colonialists began buying Africans from the West Indies and after 1680 they were purchased directly from Africa.⁷⁰ Those Englishmen who worked the fields did so as indentured servants, not slaves. Despite this hard fieldwork, they enjoyed the luxury of knowing that after a term they would be free. Even the Irish men and women were bought and sold but not as slaves, as indentured servants.⁷¹ There are several reasons for why it was convenient to use the Negro as forced laborers over other Englishmen and Indians. According to Barbara Jean Fields, Professor of American History at Columbia University, Englishmen knew the limits of oppressing people of their own kind. The reason, she suggests, came from centuries of class war in England to where respect of the lower class was won. She states, "Each new increment of freedom that the lower classes regarded as their due represented the provisional outcome of the last round in a continuing boxing-match and established the fighting weights of the contenders in the next round."⁷² In other words, freedom was an inheritance for them, especially in the New World and the Englishmen had governmental support back home.⁷³ To defy this would have sent a shockwave back to England thus affecting the migration

of other Englishmen to the colonies. In addition, Englishmen in the colonies were armed and would have waged war in defense of their freedom. On the other hand, the Africans and Indians had no such history or pseudo-covenant. The Africans and the Indians from the West Indies were already accustomed to being enslaved and would put up the least resistance.

There was a Maryland statute in 1639 that stated, “all the Inhabitants of this Province being Christians (Slaves excepted) shall have and enjoy all the rights, liberties, immunities, privileges and free customs within the Province as any natural born subject of England.”⁷⁴ Remember, it was not right for a Christian to hold another Christian in bondage. This statute confirms the presupposition that slaves were savages to the typical Englishman. After 1640 in Virginia it became apparent that some Negroes were being treated as slaves. Court records from that time indicate that “Negroes” would be for sale for life along with any children born of them.⁷⁵ In Maryland and Virginia there were a series of actions taken after 1660 to put into law exploitive conditions against Negro slaves that would be sustained for centuries. In the 1660s, the price of tobacco began to fall and so did the number of European immigrants.⁷⁶ This was one of the pivotal moments in Virginia that would influence the course for many other Southern states. As the number of European immigrants fell and the terms of those indentured, typically Welshmen and Scotsmen⁷⁷ expired there developed a glut of freed European servants who wanted land. Concomitant with this situation was the decision to monopolize all the land forcing servants to either rent from the landowners and continue working on the land or blaze into unchartered terrain in the western frontier, which was inhabited by Indians.⁷⁸ By increasing the number of Negro slaves, the plantation labor pool was satisfied and it

warded off stirring unrest amongst the former European servants who were now free and armed.⁷⁹ Virginia law prohibited Negroes from bearing arms.⁸⁰ After a while, the threat subsided. This was not only a decision to keep peace but was also a decision that further evidenced the exploitation and dehumanization of the Negroes. In 1661 Virginia passed a statute declaring that Negroes serve for life⁸¹ while in 1664 Maryland passed a similar law.⁸² In 1671 the naturalization of foreigners became law in Virginia so that they could benefit from “all such liberties, privileges, immunities, whatsoever, as a natural borne Englishman is capable of.” Maryland followed soon thereafter.⁸³

The dehumanization was further displayed in a couple of other ways. The price for Negro slaves was higher than for White indentured servants. The reason for this was because of the economic importance of the Negro. The higher figure correlated to the longer years of service. The Negro women were valued higher because their “issue” or their children counted towards future slave stock.⁸⁴ It has been reported that by 1860 the slave population had grown so much that their value to the American economy was estimated at around four billion dollars.⁸⁵ Europeans being sold for service were referred to by their full proper names; Negroes were not afforded equal dignity and instead was issued the following qualifier on the rolls: a Negro man or a Negro woman.⁸⁶ There was also a transition in terminology. As Englishmen made reference to themselves, through direct or indirect relation to slaves, they first referred to themselves as Christian, then free or English, and lastly it became White by the time 1680 rolled around with “Christian” eventually fading away.⁸⁷ Skin color became the definitive standard of distinction with White becoming the norm and everything else inferior. This was not an invention, for as previously mentioned, this form of thinking had its roots in Medieval Europe.

By the time the 18th century came around, chattel slavery was well underway in every English colony.⁸⁸ One thing to note is that also by this time, particularly by the first quarter of the century, one-third of the population in English colonies was Negro and by the middle of the century some Whites lived in neighborhoods where Negroes outnumbered them.⁸⁹ This created two problems. The first was this surge in population created an imbalance in representation in national government. The second problem, which contributed to the first, was that English colonist were confronted with actually treating Negroes as property in their accounting which proved enigmatic.⁹⁰ Governmental representation would be a problem that would create the seed of contention between the North and the South en route to and after the Civil War, which will be discussed in the next section.

While considered property, exposing a Negro woman completely naked on the auction blocks was nothing that required a second thought. The introduction of harsh discipline upon the Negroes gave rise to further dehumanization and the pathway to mistreatment as a means of establishing law and order. There was a progression in severity of punishment as one traveled from the northern colonies to the south, the tradition being the imposing of “thirty-nine” lashes with the whip.⁹¹ The worst form of punishment was either burning at the stake⁹² or the impaling of a Negro’s head on a pole and placing it in public squares to deter misconduct.⁹³ If a slave should die at the hands of a master from a disciplinary action, he was given prosecutorial immunity as long as the type of correction was perceived as “moderate.”⁹⁴ While an action is judged “moderate” or not is highly subjective, this shows that those responsible for oversight had some degree of sensitivity to the human cause in response to what appeared to be unrestraint on

the part of slave owners. Jordan shares the story of a mulatto girl in Maryland who had both of her ears cut off by her master and mistress because of what they described as disobedient behavior. The Maryland legislator freed her from what they considered was abuse.⁹⁵

Life for a slave on a plantation varied from plantation to plantation. On some plantations the masters subjected their slaves to extremely harsh labor in the fields while on other plantations the masters were a little more lenient. According to recalled accounts of former slaves, Ira Berlin, et al. shared the following account from Sarah Gruber. In recalling the conditions in which she and others had to work Sarah said, “ Ole Hoss he send us niggas out in any [kind of weather], rain [or] snow, it [didn’t matter]. We had [to] to [to] the [mountains], cut wood [and] drag it down [to] the house. Many [of the] time we come in [with our clothes] stuck to [our poor old] cold bodies but it wasn’t no use [to try to get them] dry. If [the] Ole Boss or [the] Ole Missie see us [they] yell: “Get on out [of hear you] black [thing], and [get] [your work out of the way]” [And] we know’d [to get] else we [get the] lash. [They] didn’t [care] how ole [or] how young [you] was, you [never] to big [to get the] lash.”⁹⁶ When referring to how they were fed, she said, “...the overseer give them fifteen minutes to [get] dinner. He’d start cuffin’ some of them over the head when it as time to stop [eating] and go back to work. He’d go to the house and eat his dinner and then he’d come back and look in all the buckets and if a piece of anything that was when he left was [eaten], he’d say you was [losing] time and had to be whipped. He’d drive four stakes in the ground and tie a nigger down and beat him till [he was] raw. Then he’d take a brick and grind it up in a powder and mix it with lard and put it all over him and roll him in a sheet. It’d be two days or more [before] that nigger could

work [again].”⁹⁷ Recounting another situation, she stated, “I [saw] one nigger done that way for stealing a meat bone from the meat house. That nigger got fifteen hundred lashes.”⁹⁸

Not all Negroes were slaves. In 1772 the Governor of Georgia permitted an African immigrant woman from Gambia to be free by issuing her a certificate permitting her to “pass and repass unmolested...on her lawful and necessary occasions.”⁹⁹ Despite this perceived gracious act by this Governor, it did not mean that others who were free elsewhere were freed from less humiliating treatment. There was a suspicion among Whites that freed Negroes were more loyal to their fellow Negroes who were in bondage than they were to those who allowed them to maintain their freedom.¹⁰⁰ As not all Negroes were slaves so also not all Negroes worked on plantations. Some were trained and hired as skilled craftsmen. They were trained as blacksmiths, carpenters, shoemakers, metal and ironworkers and machinists.¹⁰¹ This created animosity of another sort because Whites did not want to compete with Negroes for jobs they too were qualified to perform. However, economically, the Negro was the better bargain.¹⁰²

Over a period that would last four hundred years, beginning in 1444, some forty million Africans would be taken off the continent with the intent of enslaving them. Twenty million made it. The rest died before leaving their homeland or en route.¹⁰³ During these four hundred years social and economic life in Africa was destroyed and even resulted in tribal warfare.¹⁰⁴

3.2.2 Negroes and the Revolutionary War

It was a fourth of July celebration in Rochester, New York. The year was 1852 and Frederick Douglass was the featured speaker. Douglass, in his speech, was reflecting

back to the sought after independence from Britain penned on July 4th 1776 during the early stages of the Revolutionary War. As noted in the previous section, the thirteen colonies at this time were mired in the economy of slavery, some more deeply than others. But what is not often recorded is the significant contribution slaves and free Negroes made in the Revolutionary War. The famous Minutemen were both Negro and White and so when Paul Revere rode through the streets in Massachusetts he was alerting an integrated cavalry.¹⁰⁵ At first Negroes were barred from fighting at the order of General George Washington due to a number of reasons ranging from the negative assumption that the Negroes were poor fighters to the compassionate reaction that the Negro should not be fighting for the White men. But a certain turn of events caused him to rescind his order. For one, it was difficult to find White men who would enlist and secondly pressure continued to mount after the Governor of Virginia, Lord Dunmore issued an offer of freedom to all male slaves who were willing to fight. This caused a mass exodus of slaves leaving their plantations and masters.¹⁰⁶ By the end of the war more than 100,000 slaves were manumitted, some because of the spirit of the Declaration of Independence and others based on the promises rendered.¹⁰⁷ But not all slaves fared well after the war. The story is told how a slave and Negro naval captain from Virginia, Mark Starlin, courageously raided British ships in Hampton Roads only to be returned to slavery after the war.¹⁰⁸

As this war was for the promotion of the rights of men the groundswell of supporters were galvanized around this ideal. To that end Negroes began petitioning the courts and filing lawsuits urging the extension of these rights to include Negroes. Eventually slavery came to an end in the North and various states began gradually

emancipating their slaves. Pennsylvania for example noted the importance of proving their appreciation for their marked freedom from the tyranny of Great Britain “by extending freedom to those of a different color by the work of the same Almighty hand.”¹⁰⁹ Things seemed to be improving in regards to the treatment of Negroes. Those rising from the ashes of hostility were people like Phyllis Wheatley, a highly regarded and internationally recognized poet who was born in Africa but bought by a family in Boston. Phyllis would befriend President George Washington. Others include Benjamin Banneker, the son of former slaves, would rise to be a principal surveyor and architect in the design and construction of Washington, D. C.^{110,111} But what seemed promising would only be a dream for Blacks. Slavery still existed in the South and in the North; Blacks were assaulted and insulted, taunted and harassed. There was an increase in racial hostility.¹¹²

Even though slavery had ended in the North, life after the war was tenuous for Negroes. By the turn of the century, their lives were constricted by rules and laws and many were forced to live in segregated communities for they were not wanted. The Negro was an invasion to White utopia despite being free. Some states such as Ohio and Illinois barred them from admittance.¹¹³ The period between the Revolutionary War and the Civil War was becoming a tinderbox. Negroes could not find work in the North because they were competing with Irish immigrants that had come to the United States in an effort to escape the potato famine in Ireland. The tension was growing as these immigrants were assaulting Negroes. In addition, their homes and churches were set on fire.¹¹⁴ But the Negroes persisted in being heard and continued demanding the same rights afforded to Whites that were fought for during the Revolution. These were frustrating moments and

the American Dream in the minds of many Negroes was becoming a nightmare. President Abraham Lincoln was elected President of the United States, a nation that was really divided north and south and primarily over the issue of slavery. Despite Lincoln's eventual proclamation to emancipate slaves in 1863, he was one who knew slavery was wrong but was not willing to go as far as promoting social and political equality for Negroes.¹¹⁵

3.2.3 Post-Civil War Reconstruction

The period after the Civil War is known as Reconstruction and it is considered the most transformative period regarding government configuration and societal interactions as the nation wrestled with, not only emancipated slaves, but also federalism, citizenship, equality and rights.¹¹⁶ Before looking at life after the Civil War it is important to mention that this war was a shot in the arm for many Negroes. Many slaves left their owners and plantations to join the Union Army in the North, which ironically started in 1863 - the year the Emancipation Proclamation was issued.¹¹⁷ In the army slaves felt they were actually equal to Whites because they were treated as such in accordance to military law and it was also in the army that many of them learned how to read and write.¹¹⁸ Some believe it to also be true that the Northern troops would not have won the war if it were not for the "Negro." Even the Negroes in the northern free states felt a new gust of wind in their sails due in part to the Civil War.¹¹⁹ The War and what was to follow opened the door for significant changes regarding civil rights in the Constitution.¹²⁰ It is interesting to note that the framers of the Constitution were deliberate in the choice of wording. The Constitution was constructed with the intention of configuring an inherent weakness of

the Federal government in regards to its relation to states rights and private property. Even James Madison, the fourth president of the United States and a principle architect of the Constitution felt that it was important that in letter, if not in spirit, the Constitution should protect the interests of a few wealthy over the populace.¹²¹ Several states such as California, Illinois, and Ohio abandoned their discrimination laws, which formerly prohibited Negroes from either entering the state, or had segregated public accommodations.¹²² While the slaves were already living in confinement, free Negroes in the north still faced challenges of their own, especially due to the famous decision rendered by the Supreme Court in the *Dred Scott v Sanford* case in 1857. The Supreme Court decision basically upheld the notion that based on the Constitution the “Negro” was not a person,¹²³ (three-fifths of a person)¹²⁴ and therefore not a citizen of the United States.¹²⁵

As explorers migrated westward establishing new territories, and as a result of the territory now acquired through the Mexican-American War the question arose whether or not slavery could be established in these new frontiers. The Missouri Compromises of 1820¹²⁶ and 1850¹²⁷ each were based on Congressional tensions regarding the advancement of slavery in Northwestern territories. This issue of slavery was now the “smelling salts” that was awakening a consciousness, albeit narrow. For the first time it became obvious that this “Frankenstein” known as slavery was getting out of control and a line in the sand had to be drawn.¹²⁸ More importantly, the Compromise was necessary in order to maintain a representational balance in Congress because of how the population of slaves factored in the census. In addition, not only was there a tension in Congress over the issue of slavery but tension also existed around the power and reach of

the federal government over state and personal matters and civil liberties. With the ending of the Civil War and the institution of slavery declared illegal, civil rights and state sovereignty became the focus. Former slaves, Negroes in the “free” states and Whites who were supporters of the Negro cause were looking for protection against the various assaults from southerners unhappy with the dismantling of slavery.¹²⁹ Because of what was viewed by many Negroes as a “lose-lose” environment leading up to and during the Civil War, which ended in 1865, there was an emigration movement developing. To the emigrants, slavery was “completely interwoven into the passions and prejudices of the American people.”¹³⁰ Many Negroes felt it was in their best interest to leave a land where they were unwanted and return to Africa and the Caribbean. It is reported that over twelve hundred people emigrated to Liberia from South Carolina and Georgia.¹³¹ But as previously mentioned the Civil War and the months afterwards catalyzed a new spirit and energy among Negroes and the interest in emigration began to wane and eventually dissipate.

The period from 1866 to 1875 was a crucial time period. It was a period of hopeful liberation and victory for former slaves, Negroes in “free” states and abolitionists by way of legislative actions. Reeling from the inertia of the war, more and more Negroes began to enter politics and realized other advances in civic and political life as they sought for the recognition of equal rights.¹³² John S. Rock, a physician, lawyer and civil rights activist was the first Negro to practice before the Supreme Court in 1865.¹³³ During this period there were three amendments made to the Constitution, the Thirteenth, Fourteenth and Fifteenth Amendments. The Thirteenth Amendment declared that "Neither slavery nor involuntary servitude, except as a punishment for crime whereof the

party shall have been duly convicted, shall exist within the United States, or any place subject to their jurisdiction."¹³⁴ Also attached to this amendment was a civil rights bill, passed in 1866, that declared all persons born in the United States were citizens of the United States, an act that overturned the *Dred Scott* ruling of the previous Judicial Court.¹³⁵ It was expected that with the passage of this amendment, former slaves were not only freed but that they would be afforded the minimal rights as well as protection for them and their White supporters by the Federal government, through Congressional action, against such abuses as kidnapping, imprisonment and murder from White oppositionists in the South. But that was not to be the case for despite the amendment, these atrocities continued.¹³⁶

The Freedman's Bureau was established by act of Congress in March 1865 for the sole purpose of providing temporary support for the integration of former slaves into society. The Bureau provided assistance for Negro veterans, built hospitals, negotiated labor contracts for former slaves, and legalized marriages.¹³⁷ Some of their work gave rise to the hopes of many former slaves that they would receive a share of the properties they labored on for years through land distribution.¹³⁸ But this too was met with great opposition, one important oppositionist being President Andrew Johnson.¹³⁹ The Bureau created close to 100 hospitals for the emancipated but in three years time the only hospital that remained in existence was the Howard University Medical Center.¹⁴⁰ Other responses to the Thirteenth Amendment included the incorporation of "Black Codes" in many southern states. Mississippi and South Carolina were the first states to enact them. One of the things these codes required was for "Negroes" to have written documentation proving employment or they would be subject to fines or imprisonment.¹⁴¹ However,

while the amendment sought and successfully illegalized slavery, suffrage for the Negro was still a right and privilege out of reach.

The Fourteenth Amendment of 1868, offered citizenship to “all persons born or naturalized in the United States,” including former slaves. It also, forbids states from denying any person “life, liberty or property, without due process of law” or to “deny to any person within its jurisdiction the equal protection of the laws.”¹⁴² Because of the perceived shortcomings of the Thirteenth Amendment and the continued abuses toward Negroes it was the intent of the framers of this amendment to incorporate language to ensure ““full protection in the enjoyment of life, liberty and property”” and to make sure Congress had the power to make certain of it.¹⁴³ It embraced Negroes and Whites equally, establishing a national citizenship unable to be abridged by any state.¹⁴⁴ Such was the antagonism at that time that it was believed that if they did not include such language guaranteeing citizenship for the “Negro” then there would be efforts to revoke citizenship and through interpretation, resort back to the effects of the *Dred Scott* decision.¹⁴⁵

On February 3, 1870 Congress passed the Fifteenth Amendment.¹⁴⁶ This amendment “granted African-American men the right to vote by declaring that the “right of citizens of the United States to vote shall not be denied or abridged by the United States or by any state on account of race, color, or previous condition of servitude.”¹⁴⁷ Later in 1870 Congress passed a civil rights act, which provided “the right to free suffrage without distinction as to race, color or previous condition of servitude” and imposed criminal penalties on anyone who “inhibited” the right for anyone to qualify or register to vote.¹⁴⁸ Warranting even more poignant measures, Congress passed the Ku Klux Klan Act in 1871 to further enforce the Fourteenth Amendment and in response to

vigorous activities in the South.¹⁴⁹ It granted President Ulysses S. Grant the authority to use military force and impose heavy sanctions and martial law against terrorist organizations.¹⁵⁰

The Civil Rights Act of 1875, built upon the Fourteenth Amendment, was an attempt to allow victims of discrimination to bring the accused before a federal judge for the possibility of facing fines and even possible imprisonment if convicted. The overall objective of the Act was to end discrimination in both its public and private forms.¹⁵¹ What would, contextually, appear to be the genius of the effort in crafting this legislation was that it did not focus explicitly on equal rights for the Negro because of the catalytic nature of the issue. Instead it focused on protection for travelers and in so doing relied on the longstanding history of British Common Law, particularly the Innkeeper law.¹⁵² Under the Innkeeper Law, innkeepers had a duty to provide accommodations to anyone who had the ability to pay. Secondly, the innkeeper was obligated to provide food and drink. Finally, the innkeeper was responsible for protecting the property of guests; otherwise, if property were lost or stolen the innkeeper was responsible for compensating the value of the loss.¹⁵³ The buildup of the use of this Common Law was based on the premise that despite the private interests of the Inn, it was still a public institution and therefore subordinate to the common good.¹⁵⁴ What was intended in England when those laws were established and what the legislature in America was also hoping to establish was the tradition of a “well-regulated society.”¹⁵⁵ According to Sandavol-Strauss, “The protection of travelers that operated in eighteenth-century North America marked the colonists’ adoption of pre-modern legal regimes that had existed for centuries before the emergence of Enlightenment inspired ideas of individuality and rights.”¹⁵⁶ Some states

already had statutes on the books that embodied such protections. For example, in 1786, Massachusetts had a law that required innkeepers ““convicted of refusing to make suitable provisions when desired, for the receiving of strangers, travelers, and their horses and cattle, ‘would be’ deprived of his or her license.””¹⁵⁷ Eventually legislators in the South during Reconstruction sensed a door opening for an egalitarian premise with the common law. They were so determined to not allow Negroes the opportunity to equal treatment that Delaware modified its common law for innkeepers and Tennessee abolished theirs. After the passage of the Civil Rights Bill of 1875 Negroes tried to capitalize with local actions in the South that eventually spread. The response to this potential movement was innkeepers and other proprietors choosing to close their doors rather than adhere to the new law.¹⁵⁸

Amid the Congressional advances for civil rights there was a slow erosion of the efficacy of these bills and amendments. Southern powerbrokers never accepted equal rights for Negroes, economic advancement or the right to vote. They especially were not in favor of nationalism because of, in their perspective, the intrusion of the federal government in what they believed were solely matters of the states. The Fourteenth Amendment came under heavy attack; the subject was its privileges and immunities clause. This clause, known also as the comity clause, stated that all citizens of every state “shall be entitled to all privileges and immunities of citizens in several states.”¹⁵⁹ By the end of the 19th century the Supreme Court had declared the Amendment null and void in the South.¹⁶⁰ It was the *Slaughterhouse Cases* from which the unraveling began. The Supreme Court through its interpretation resolved that the Fourteenth Amendment’s application was too broad and that the rights associated with national citizenship only

included those that were outside the bounds of the state thereby rendering the punitive sanctions useless – a severe blow to civil rights.¹⁶¹ Furthermore, following the *Slaughterhouse Cases* was *United States v. Cruikshank*, which challenges the right of the “Negroes” to assemble. Applying the logic from the *Slaughterhouse Cases*, the Supreme Court ruled that peaceful assembly is not a right of national citizenship unless it is related directly to actions of the federal government thereby handcuffing the federal government from getting involved in any matters that do not solely involve the citizen and the federal government.¹⁶² Lastly, the Court decided that the Fourteenth Amendment did not “add anything to the rights which one citizen has under the Constitution against another.” In other words, actions of private individuals are outside the legislative bounds of the federal government.

As stated above, the interpretation of “freedom” for Negroes was something that would continue to be challenged. It’s important to note that Negroes were not bystanders in the movement for liberation and equality but expressed their desires with voracity and tenacity. Reconstruction ended in 1877 but according to Eric Foner, it was not because of economic coercion but because Negroes were victims of fraud, violence and national abandonment.¹⁶³ The national abandonment was due to the judicial tyranny of the Supreme Court. Foner further states, racism was so combustible that its dismantling of Reconstruction led to the effusive disenfranchising of blacks with a longstanding vigor that even in the 20th century the cultural and political climate remains saturated with its odor.¹⁶⁴ Eugene Gressman, in commenting on the legislative activity from 1866 to 1875, notes, “Never before or since has there been so much important federal legislation regarding civil rights.”¹⁶⁵ In the end, the Supreme Court demolished the ancient tradition

that the protection of travelers was the responsibility of the public. Commensurate with this spirit was the shift from community obligations to jurisprudential rights for individuals and property.¹⁶⁶ How this affected Negroes was quite varied and created a hardship for their travel both intra-state and inter-state because now with the emasculation of the Civil Rights Act, Negroes could not get redress from the federal government and authority and power regarding individual treatment was in the hands of the states and local municipalities.

3.2.4 African-American Life in the Twentieth Century

By the turn of the twentieth century the anti-Black attitudes and legislation to support them was well entrenched in the fabric of the United States. This was lived out in several ways. Oklahoma required segregated phone booths, Black students could not be taught by White teachers; Florida required textbooks for Black and White students stored in separate warehouses and in South Carolina Negro and White cotton mill workers were forbidden from looking out of the same windows.¹⁶⁷ In the South only three states did not require segregation on railroad transportation and by 1901 states mandated segregation in every aspect of life.¹⁶⁸ In the early 1900s, Georgia, Virginia, South Carolina, Arkansas, Tennessee, Mississippi, and Maryland all required Jim Crow seating on their streetcars while in Mobile, Alabama Blacks were prohibited from being on the streets after 10pm.¹⁶⁹ One would wonder why during slavery there would not be segregated facilities even for free Blacks. Bennett suggests that the reason behind this was as long as the Negro was a slave he was not a threat to the political and economic life of Whites but once he became a citizen that changed everything.¹⁷⁰

In 1870 the Fifteenth Amendment granted Black men the right to vote. As the twentieth century was getting underway this was a matter the South was considering restricting. Voting meant power and southern Whites wanted to constrict any possible benefit of citizenship, voting included. The challenge the Whites faced was figuring out how to disenfranchise Blacks without disenfranchising poor whites. What they decided to do was implement poll taxes and literacy tests. However, in order for poor Whites to not get caught in this net, a grandfather clause was used. Simply, if one's ancestors were permitted to vote prior to 1866 then an exception would be made. This obviously excluded all Blacks.¹⁷¹ To demonstrate the effectiveness of these draconian measures Louisiana in 1896 had over 130,000 Black voters. In 1900 there were a little more than 5,300 due to the grandfather clause inserted and adopted in the Louisiana constitution.¹⁷²

Perhaps the most brutal of all the exploits in the South during this time was the lynching. It had previously been reported how slaves, both women and men, were whipped until their backs were raw. But at that time slaves were property. In the 19th century Blacks were free. It has been estimated that in the early 1900s a Black was lynched somewhere about every two or three days. Lynching became sport to the southerner. Newspaper ads would announce an upcoming lynching, when and where and the reasons for taking a life in this manner were unjustifiably for the most miniscule of acts such as not saying "Mister" to a White man, looking for other employment or even testifying against a white person in court.¹⁷³ E.M. Beck and S.E. Tolnay report that from 1863 until the Great Depression, there were over 3,000 Blacks lynched in the South and research has not found consistent evidence for motives. It has been hypothesized that Blacks were a perceived economic and political threat to Whites who wanted to maintain

their social superiority. But the only thing that has been empirically consistent is that whenever cotton production was low, lynchings increased; whenever cotton production was high, lynchings decreased. When production was down Whites were substituted for as laborers and lynching was the intimidation factor.¹⁷⁴ Southern Whites were divided into two classes. One class consisted of planters and employers while the other group consisted of sharecroppers, day laborers and tenant farmers. When the economy began to decline rural Whites were uncomfortable competing against Blacks for jobs, a group of people conceivably and perceptively inferior to them. Therefore, White mob violence was the answer.¹⁷⁵ The last recorded lynching took place in 1964 and by then they had taken place in forty-nine states as far north as Maine and Vermont.¹⁷⁶ Harkening back to the “Black codes” that went into effect as a southern response to the Thirteenth Amendment, chain gangs were setup. This was also known as “convict leasing.” Blacks were arrested and convicted for crimes as simple as “vagrancy,” sentenced to hard labor in turpentine and mining camps as free labor for industrial enterprises.^{177,178} The story is told of a 22-year-old young man named Green Cottenham who was arrested and charged with vagrancy in Shelby County, Alabama. He was sentenced to work in the coalmines of the Tennessee Coal, Iron & Railroad Company, a subsidiary of the U.S. Steel Corporation. For the \$12 per month this company paid to the county to cover Green’s fines and fees they had the right to do as they pleased with him. Green was sentenced to the mines where other men were serving lengthy sentences and subjected to tuberculosis, pneumonia and other diseases. Many died without finishing their terms. Their bodies were either burned in the incinerator or buried in shallow graves.¹⁷⁹ As Douglas Blackmon states, this was slavery by another name.

Concomitant with the violence in the South was growing activism by Blacks in both the North and South. There was an apparent portal that could allow for federal protection of Blacks. When the Interstate Commerce Commission was established in 1887 it included a provision allowing Black travelers to bring allegations of discrimination to federal officials. While this was also a trigger point for increased segregation in the South, Blacks used this agency as its on-ramp for justice.¹⁸⁰ According to Sandoval-Strausz, “Commerce power became a new means by which nineteenth-century protection of travelers were federalized and extended to all Americans in all categories of public space in the twentieth century” due to its redefinition under President Franklin D. Roosevelt’s New Deal.¹⁸¹ A few key Supreme Court decisions began to chisel away pieces of the Jim Crow structure. Arthur Mitchell, a Black Congressman from Illinois, filed a complaint with the Interstate Commerce Commission after being ejected from a Pullman car in 1937. His complaint eventually reached the Supreme Court in 1941 where he won a unanimous judgment stating that it was unconstitutional to deny Blacks access to such facilities. A second was *Morgan v. Virginia* where a Black woman traveling to Baltimore, Maryland was arrested and fined for failing to comply with Virginia’s segregation law by giving up her seat to a White person on a Greyhound bus in 1944. The Supreme Court ruled that in reference to interstate travel, Virginia’s law was unconstitutional in 1946.^{182,183} This occurred nearly a decade before the more famous incident with Rosa Parks on a bus in Montgomery, Alabama. Lastly, the Supreme Court again ruled unanimously against segregated dining car facilities in *Henderson v. United States* in 1950. Sandoval-Strausz makes an excellent point in noting that these cases stayed clear of the equal protection provision of the Fourteenth Amendment and instead

relied on the Constitution's commerce power for interstate travel.¹⁸⁴ Apparently, this was the most expedient and uninhibited route to justice, given judicial precedence. But in actuality the constitutional language of equal protection was not in play because equality was still a dream deferred for Blacks and a reality denied for Whites. Oppositions, however, would not concede without a fight. Recognizing the longstanding tradition of common law with the concerns for the welfare of the traveler and innkeeper duties, legislators that favored segregation began implementing state laws that derided federal rulings. Delaware, as an example, created legislation permitting innkeepers, restaurant owners and other places of public accommodation to refuse to serve anyone who in their mind would pose a threat to their business. Mississippi, Louisiana and Tennessee followed in similar spirit.¹⁸⁵

In 1954 another seminal decision of the Supreme Court was rendered. It was *Brown v. Board of Education*. This case centered on desegregating public institutions, particularly schools. The justices in this case argued that racial segregation of children in public schools violated the equal protection clause of the Fourteenth Amendment.¹⁸⁶ This was a clear departure from previous court decisions that seemed best to ignore this amendment and navigate through the innkeepers and travelers language of common law. However, while this landmark decision ruled in favor of desegregation, the ultimate goal of equality in the minds of Blacks was still not achieved. Yosso, et al., argue that the failing of this Supreme Court ruling fell short in that it did not require a timetable for school desegregation and also assumed that school integration would also mean equal education for Black students.¹⁸⁷ However, that was not the result then and even today educational equality between Blacks and Whites is a chased reality.

As the new Civil Rights Movement was getting underway, it became apparent to oppositionists that arguing to preserve segregation in the manner in which it had been offered in the past was futile. Instead they introduced the neutralizing and galvanizing term “law and order.” In this new move, governors in the southern states in conjunction with law enforcement began attacking acts of civil disobedience performed by Dr. King and others, as criminal activity in violation of the preservation of order even though the protests were in response to the abuse of law enforcement.¹⁸⁸

When John F Kennedy became president in 1960 it was obvious that he and his administration was mindful of how dependent his election was on the southern White voters and that civil rights was not on their immediate agenda.¹⁸⁹ But it was the work of the southern leadership of Rev. Dr. Martin Luther King, Jr., the Southern Christian Leadership Conference, the groundswell of young activists such as the Student Non-Violent Coordinating Committee and others in the North through direct actions and civil disobedience that helped expose the atrocities directed at Blacks. After the assassination of President Kennedy and the assumption of the presidency by Lyndon B. Johnson the Civil Rights Act of 1964 became law. Although this was an omnibus bill with interests fanning a number of areas, like its 1875 predecessor civil rights bill one of its focuses was on public accommodations.¹⁹⁰ As could have been expected this act was put to the legal test by southerners. One such case was *Heart of Atlanta Motel v. United States* in 1964 where a motel owner claimed that the federal government had exceeded its power through the use of the commerce clause in regulating private businesses and violated the Fifth Amendment denying the proprietor the right to “choose its customers and operate its business as it wishes, resulting in a taking of its liberty and property without due

process of law and a taking of its property without just compensation.”¹⁹¹ The Supreme Court decision was unanimous in upholding the Civil Rights Act. Once the Act passed there was a more intentional shift from segregation to crime and politicians who had originally voted against the Civil Rights Act crafted crime legislation.¹⁹² This was part of the buildup to the eventual mass incarceration of African-Americans. Michelle Alexander, in her scholarly work on mass incarceration, remarks, “The valiant efforts to abolish slavery and Jim Crow and to achieve greater racial equality have brought about significant changes in the legal framework of American society.”¹⁹³ She argues further that through such political manipulation, leaning heavily on the virulent strain of racism and vulnerable poor Whites, a new caste system has been birthed to where these poor Whites will go along with whatever will prevent them from scraping the bottom of the social hierarchy.¹⁹⁴ In 1968, the year Dr. Martin Luther King Jr., and Senator Robert Kennedy were assassinated, a Gallup poll revealed that most people felt that “law and order” was ineffective and the primary culprits were African-Americans.¹⁹⁵ This planted in the minds of many a justification to demonize African-Americans and characterize them as dangerous. In addition to being characterized as menaces, African-Americans were also being presented by Conservative Republicans as governmental drains as welfare recipients which was a targeted message to working class Whites.

During the Nixon presidency a war on drugs was declared but it wasn’t until 1982 when President Ronald Regan announced a war on drugs and reinforced it with a strong media campaign. The increase in funding from Congress to the Department of Defense, FBI, and the Drug Enforcement Agency was significant over the 4-year period from 1980-1984 while government funding for drug treatment, prevention and education

programs was significantly reduced. Alexander states that this war on drugs was not about the public opinion on drugs but on the public opinion on race.¹⁹⁶ The irony in this maneuver is that when this war on drugs was declared, it wasn't long afterwards that crack cocaine made its way into the inner cities. If this smelled like a conspiracy it is because it was. Gary Webb, a journalist for the San Jose Mercury, reported that a drug ring in San Francisco supplied cocaine to the area street gangs with the profits that were redirected to fund the Contras in Nicaragua all under the watchful eye of the United States Central Intelligence Agency. This network would expand and drugs from Columbia would find its way into the inner-city African-American communities of Los Angeles.¹⁹⁷ This story later became a motion picture about the allegations of a government conspiracy and cover-up. Concomitant with the drug distribution within the inner city was the change in drug sentencing through the Anti-Drug Abuse Act, which imposed a mandatory minimum sentence of 5 years in prison and a felony charge just for simple possession with no intent to distribute.¹⁹⁸ Alexander reports that according to the Sentencing Project, in 1991 twenty-five percent of African-American men were "under the control of the criminal justice system."¹⁹⁹ Loïc Wacquant from the University of California-Berkley reflects on the three "peculiar institutions" in the United States. He identifies them as slavery, Jim Crow, and the ghetto. For Wacquant, the ghetto is a "social prison" and together with the other two was designed to promote cheap labor for the economic gain of the industrial enterprise and for socially ostracizing African-Americans as a means of promoting the social hierarchy.²⁰⁰ The infusion of drugs into the urban ghetto in the 1980s and 90s took advantage of the economic depression of African-Americans living in concentrated poverty and continues to exploit that reality today. The

number of prisoners between 1980 and 2007 increased from an estimated 300,000 to 7 million Americans, two-thirds of which were imprisoned for drug offenses.²⁰¹ The corresponding imprisonment has led to a disproportionate share of African-American inmates.²⁰² Pettit and Western state that prison has become the new normal for African-American adolescents and early adults and that social inequalities may have worsened as a result of the systemic incarcerations during the 1980s and 90s.²⁰³ They further state that this can be due in part to the fact that “having a prison record can confer a persistent status that can significantly influence life trajectories.” This prison industrial complex has not only affected men but women are also being affected either because of direct involvement in drug trafficking or because they are guilty of possession without the intent to distribute by association with someone who quite possibly is a distributor. The percentage of African-American women in prison is higher for the female population than the African-American male is for the total male population. Between 1986 and 1991 the number of African-American females incarcerated between 1986 and 1991 increased 826%.²⁰⁴ Later it will be discussed how the female population has been manipulated for medical mistreatment.

A history of the chronic challenges of being an African-American in America has just been conveyed. More can be shared about how this mass incarceration movement has successfully put in place a system designed to confiscate from felons their civil liberties that were fought for vigorously in the past. Therefore the next section will examine the effects of racism and other forms of discrimination on the health of African-Americans as well as the discriminate forms of health care offered to them over the years.

3.3 Races, Bias, Mistreatment and Under-treatment in Health Care for African-Americans

The history of discrimination outlined above reveals the systemization of a culture designed to keep Negroes, who later began to be referred to as African-Americans, controlled and confined to the abnormal pressures of daily living. To say that this sort of environment did not have an effect on their health would be disingenuous and shortsighted. When discussing medical abuse of African-Americans through therapy and research the Tuskegee Syphilis study seems to be the episode that is presented as the incomparable evidence of abuse in medical history. But scholars such as Harriet Washington, Dorothy Roberts and Herbert Morais have uncovered and reported on countless other examples of abuse. This section will provide a chronological overlay of the medical mistreatment of the slaves that coincided with the other abuses mentioned above. This report will continue with their experiences once free, during the Reconstruction period, through the 19th and into the 20th centuries. What will also be conveyed in this section is that in the area of medicine, what was shared in the previous section was so influential that several leading US physicians initiated the justification of unequal medical treatment of Blacks based on their advocacy that Blacks were biologically inferior to Whites.²⁰⁵

3.3.1 Ripe Conditions for Medical Mistreatment in 18th and 19th Century America

The powerlessness of slaves during this time left them extremely vulnerable to the whims of not only plantation owners but also physicians. The working conditions for many slaves were brutal. With the high rate of immigration of Europeans into the country during this time, and the forced importation of slaves from Africa and the West Indies,

diseases were transported across the Atlantic and Caribbean with the same ease as the travelers' luggage. Medicines and care was not well advanced and public health was an issue in Europe. Because development was even slower in this country public health conditions were worse. The vaccines and other advances in Europe were slow to make their way to America. Diseases from Europe and Africa would converge in the tropical climate of the South where the pathogens found a fertile environment. 90 percent of the Black population in this country lived in the South at this time.²⁰⁶ Slaves would often work in the sweltering heat from sun up to sun down as well as during the bitter cold of winter. In the minds of some slave owners a healthy slave made for positive production and therefore was an investment worth protecting. In the mind of other owners if one animal went down another one would have to pick up the slack. The living conditions contributed to the short life expectancy of slaves. The cabins they slept in were overcrowded and unsanitary; the meals were sparsely nutritious, leading to higher mortality rates than Whites.²⁰⁷

Southern scientists claimed to be the experts in analyzing African-Americans due in part to their significant population in the South. The apparent science referenced by southern doctors used in their practices on slaves was completely biased and based on the historical writings from antiquity, flawed biblical interpretation, and physiological myths about Africans.²⁰⁸ As an example, Dr. Samuel George Morton published a book in 1839 titled, "Crania Americana" where he argued the positive corollary of skull size with racial typology concluding that Caucasians have larger skulls among humans with African-Americans having the smallest. This opened the way to the subsequent linkage of skull or brain size to intelligence, otherwise known as phrenology.²⁰⁹ Another well respected

physician and researcher of the time was Samuel A. Cartwright of Louisiana. He can be credited with reporting numerous fictitious illnesses solely pertaining to African-Americans. For example, some of his diagnoses were *Drapetomania*, described as an abnormal tendency of slaves to escape, *Hebetude*, which was an abnormal attitude of laziness, which led to property abuse, and *Dysthesia Aethiopica*, defined as the desire to destroy the property of White people. His remedy was physical abuse and hard labor.²¹⁰ Another physician worthy of discussing is Dr. Josiah Nott of Mobile, Alabama who purported that the knee joint and long heel of African-Americans were unique and naturally subjected them to be submissive kneelers.²¹¹ To further the insult it was theorized that Whites could not work in subtropical weather and that African-Americans were immune to Malaria thereby justifying forced labor in the periodically unsavory conditions of the South. To make matters worse, it was conjectured that African-Americans had a nervous system that made them impervious to emotional, mental and physical pain. This later led to quite violent and painful medical experimentation on African-Americans, which will be discussed in the upcoming pages.²¹²

Washington notes that for the slaves, this prolonged exposure to mistreatment and maltreatment lead to what she calls *iatrophobia*, the fear of medicine.²¹³ This was the antecedent to what has been shared in a variety of discourses over the years as the mistrust of medical science and the healthcare system among African-Americans. But the slaves came to this country with their own knowledge of how to heal certain ailments. It was within their worldview that many of the diseases were caused by spirits and so part of the recipe for remedies involved potions and conjuring spirits through incantations.²¹⁴ This practice was viewed with considerable skepticism by the European immigrants,

masters and commoners alike, and called a form of ignorance and superstition.²¹⁵ Many African-American slaves considered western medicine medical cannibalism.²¹⁶

Rarely known are the countervailing facts that there were African-Americans who practiced medicine in the 18th century and were well respected by some of the more premier practitioners in the country. Most of them learned as apprentices to educated physicians. For example, Dr. James Derham, a former slave and considered “one of the most distinguished physicians in New Orleans,” purchased his freedom because of the medical knowledge he had acquired and his adeptness of practice. Dr. Benjamin Rush, a signer of the Declaration of Independence, considered America’s leading physician of the time and a member of the Society of Arts and Sciences of Milan, the National Institute of France and the School of Medicine of Paris, had interactions with Derham resulting in the following finding: “I expected to have suggested some new medicines to him, but he suggested many more to me.”²¹⁷ There are other outlier accounts where some Whites were so impressed with the knowledge and practice of their “Negro” doctors that they would consult them over their ethnic counterpart and even preferred to have the “Black” midwives deliver their babies.²¹⁸ There are plenty more examples.

3.3.2 The Genesis and Pervasiveness of Medical Mistreatment

3.3.2.1 The Antebellum Period During Slavery

Medicine in the American South was experimental and the experimental subjects were often the expendable slaves. Informed consent was not required in those days. Yet, experimentation and treatment were conducted on slaves by the consent of the slave owners since slaves were no more than property anyway. These experiments were

hazardous in nature and would never have been practiced on Whites. For example, Dr. T. S. Hopkins of Waynesville, Georgia prescribed nitric acid to five black children diagnosed with asthma.²¹⁹ Risky treatments were explored such as the use of arsenic, chlorine and mercury along with the addictive narcotics such as opium, morphine and laudanum.²²⁰ At that time it was believed that one way to relieve the body of sickness was through the expulsion and extraction of bodily fluids. Therefore, physicians would often use drugs to induce vomiting or even a technique known as “cupping” or “trephination” was used to for “bloodletting.” The former involved placing a heated glass on the bodily surface to draw blood to the skin surface while the latter involved drilling holes in the skull.²²¹

Slave owners would often send their sick slaves to “hospitals” which typically were no more than backyard shacks or send some of their well slaves for hire to physicians for research. Some of the latter were slaves that were either too old or infirmed to work or too old for breeding.²²² Thomas Jefferson had 200 of his own slaves inoculated with the smallpox virus to qualify the safety of the vaccine.²²³ In 1832 amid a typhoid fever epidemic in Virginia, Dr. Robert G. Jennings, unaware of a cure, rounded up thirty African-Americans, free and slaves, and administered the smallpox vaccine hypothesizing the vaccine would stem the tide of the outbreak.²²⁴ According to Washington, a significant number of the articles in the 1836 *Southern Medical and Surgical Journal* were about medical experimentation on slaves. Physicians such as Dr. James Dugas and Francois Marie Prévost performed experimental eye surgery and cesarean sections on slaves respectively.²²⁵ Washington reports that the next decade saw an increase in sadistic tendencies in medical research. She reports on the work of Dr.

Walter F. Jones of Petersburg, Virginia who wanted to find a cure for typhoid pneumonia. His experiment involved placing a slave face down on the ground and pouring five gallons of boiling water on his back along the spinal column region and claimed such treatment reestablished capillarial circulation.²²⁶

But perhaps no physician was more sinister and ruthless in practice than Dr. James Marion Sims. For one, he was considered the father of modern gynecology. His experiments were primarily on children in tetany and women with vesicovaginal fistula although he did purchase about seventeen male slaves to experiment on or to work in his clinic. Sims theorized that the tetany of Negro children was due to the displacement of skull bones during childbirth as opposed to vitamin D, calcium and magnesium deficiency due to malnutrition. So his remedy was to crack open the skull of a child and with a cobbler's tool, reposition the skull.²²⁷ Sims later acquired eleven women slaves that were diagnosed with vesicovaginal fistula and experimented on them over a four-year period, without anesthesia.²²⁸ But his inhumanness went beyond his experiments with Negros. White women who suffered from vaginismus, a condition where the vaginal muscles contract making intercourse a very painful experience if not preventing it altogether, would be etherized so that their husbands could have sex with them.²²⁹

3.3.2.2 Experimentation during Post-Civil War Reconstruction

With the abolition of slavery there was a need to continue to impede any plans to allow social equality of African-Americans. Science again took the mantle. It was important to continue to promote the inferiority of African-Americans and phrenology was one means to make that happen. As mentioned previously this slightly evolved branch of science continued to theorize intelligence as measured by brain size, which was

measured by the size of the skull. What made this scientific was collection of numerical data assured as immutable. This expanded into linking personality traits to the same scientific base concluding that the propensity to violence was inversely proportional to brain size. This coincides with African-American migrations to cities. They were also labeled as fundamental transmitters of infectious diseases.²³⁰

3.3.2.3 Experimentation in the 20th Century

The Tuskegee Syphilis study is perhaps one of the most well-known examples of the inhumane treatment of African-Americans at the hands of and for the advancement of medical science. Beginning in 1932 and lasting through 1972, the government-funded experiment involved a trial of four hundred African-American men, sharecroppers in Macon County, Alabama, used to test the effects of syphilis gone untreated.²³¹ This program sponsored by the U.S. Public Health Service deceived infected men into thinking they were going to receive free medical care only to be used as guinea pigs in the study. These men were profiled as intellectually inferior, degenerate, impetuous, and sexually aggressive.²³² There were similar experiments taking place overseas. Even before informed consent became law in this country and before the Nuremberg code of 1947, there was evidence of its requirement overseas when in 1898 Dr. Albert Neisser, of the University of Breslau in Prussia, used serum therapy on syphilis patients, mostly prostitutes. Despite the support of other academic physicians, Neisser was fined by the Royal Disciplinary Court with the court also ruling that he should have sought patient consent despite the low risk of patient harm.²³³

For over forty years, beginning in 1929, the state of North Carolina administered the largest sterilization program in the country, long after other states had rolled back

their efforts in the light of the sterilization movements in Nazi Germany. More than thirty other states had eugenics sterilization programs but none to the extent of North Carolina.²³⁴ Their premise was population control, namely reducing the population of mentally and physically ill and curbing social malignancy through sterilization. The victims were primarily poor and predominantly African-American. The whole idea was that a “bad gene” was the reason for the subject’s condition. The North Carolina legislature passed a law in 1929 and rewrote it in 1933 authorizing sterilization on people that were feeble-minded, epileptic and had other sicknesses. North Carolina was also the only state where even social workers had the authority to recommend sterilization.²³⁵ This was uncovered through an investigation by the Winston-Salem Journal only to discover their complicity in the movement during that moment in history as they served as advertisers. It was discovered that the program managed to persist in North Carolina due to the self-interest and financial support of James G. Hanes of the Hanes Hosiery undergarment enterprise and Dr. Clarence Gamble of Boston, benefactor of the Proctor & Gamble chest. They argued that welfare mothers as well as the mentally ill were a burden to taxpayers.²³⁶ What is not often shared is when Germany launched its sterilization program in 1934 there were already seventeen states in this country with approved sterilization programs.²³⁷

Dr. Johanna Schoen, assistant professor of women’s history at the University of Iowa, combed through about 7000 patient records where she estimates that only about 446 of the patients desired the sterilization procedure. For some patients in mental institutions it was required as a condition of release.²³⁸ Over 2000 people under the age of 19 were questionably sterilized including a 10-year-old boy who was castrated.²³⁹ The

program ended in 1974. One such victim, Ruth Cox, an 18-year-old unwed mother, successfully sued the state of North Carolina, opening the door for other such lawsuits. This attention among others eventuated in the establishment of the 1978 Federal Sterilization Guidelines.²⁴⁰ It must be stated that some poor and minority women used these sterilization programs to their benefit. Not everyone was coerced. According to Schoen's research those who sought the program can be identified across class and racial lines thereby signifying the lack of other resources available to them.²⁴¹ While North Carolina has been the poster child for bringing this practice to light, no other state has allowed access to its sterilization records.²⁴² During the 1970s African-American women who were pregnant and wanted abortions were forced to compromise for sterilization with some physicians. It was also estimated that in Alabama between 100,000 to 150,000 poor women were sterilized every year.²⁴³ One significant point to address on the issue of eugenics and sterilization, which still has an echoing effect today, is the work of Margaret Sanger, pioneer behind women's birth control and the founder of what is known as Planned Parenthood, one of the largest charitable organizations in the country today. Sanger started the Negro Project designed to assist African-American women unable to access health services in the city. Through her family planning centers eugenics principles were used as a means of reducing the African-American population.²⁴⁴ When abortion was still illegal, it was Margaret Sanger who supported the development of the birth control pill and intentionally made it available through Planned Parenthood free to African-American women in the urban areas. This connection was already in place through the Negro Project clinics.²⁴⁵ Consistent with this are the reports of countless African-American women who underwent involuntary hysterectomies. In the South it

became so common for an African-American woman to have an involuntary hysterectomy during surgery for other issues that it became tagged as a “Mississippi Appendectomy.” But this practice was not limited to the South. In hospitals in New York and Boston, these procedures were performed on African-American and Puerto Rican women to give medical residents practice. However, in 1972 Boston City Hospital medical students raised a protest against this practice.²⁴⁶

During the 70s, again under false pretenses by the U.S. Government, seven thousand African-American children had their blood drawn for genetic screening under the fallacy that criminal activity had genetic origins. The parents were told their children were being tested for anemia.²⁴⁷ Earlier in this chapter we looked at the inequity in prison sentencing between African-Americans and Whites. Unfortunately, unsolicited experimentation also took place behind the prison walls among a population confined. Randall cites that at least 396 inmates of a state correctional facility in Ohio were injected with liver cancer cells against their will so that researchers could study disease progression in 1962. Between 1963 and 1971 over one hundred prisoners at the Oregon State Penitentiary received injections in their testicles of radioactive thymidine to test sperm production rates.²⁴⁸

As mentioned previously, the Nuremberg code was enacted in 1947 after World War II in response to involuntary human experimentation. The International Military Tribunal hearing the case in Nuremberg, Germany consisted of judges from the United States, Britain, the former Soviet Union, and France. The trial was for charges against Nazi doctors using prisoners in concentration camps for experimentation.²⁴⁹ The irony here is that in looking back, the Tuskegee Syphilis experiment and others mentioned

above continued after Nuremberg. In 1978 the Belmont Report was published after the work of National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, with the purpose of developing ethical principles and guidelines regulating research of human subjects.²⁵⁰ Congress convened this commission right after the Tuskegee experiments were halted in 1974. Yet despite these protections, evidence shows that experimentation and not therapy continues to take place in prisons. According to Washington, there are currently studies being done that require inducing labor in pregnant female inmates, testing various methods for obtaining biopsies, testing different HIV vaccines and testing the efficacy of cancer chemotherapies on prisoners. Some prisoners reported feeling coerced by prison medical staff under the guise of getting better medical care.²⁵¹ There is evidence that as late as 1989 and up to 1994, the Medical University of South Carolina in Charleston was illegally testing poor African-American women for drug use while they sought prenatal treatment. Those testing positive were reported to law enforcement and arrested, some delivering their babies in the hospital wards cuffed to their beds. Upon learning of this, the Center for Reproductive Law and Policy in New York City filed a complaint with the National Institute of Health.²⁵²

One of the more recent and insidious acts of experimentation involved the drugs Depo-Provera and Norplant. Depo-Provera had been FDA approved as a contraceptive but when it was discovered that beagles used in testing the drug developed breast cancer, they decided to no longer fund projects testing as a contraceptive. However in 1978 doctors began testing the drug as a contraceptive in research studies with African-American women the same year the drug was approved by the FDA for cancer therapy. Because the drug was legal there was nothing prohibiting doctors from administering the

drug for other uses short of ethical incongruence. Consequently, doctors administered the drug to healthy African-American and Native American women as an experimental contraceptive. In 1992 the FDA, critical of an Emory University study, stated ““Never has a drug whose target population is entirely healthy people been shown to be so pervasively carcinogenic in animals as has Depo-Provera.””²⁵³ Subsequent to this was a headline in the December 12, 1990 edition of the Philadelphia Inquirer which read, ““*Poverty and Norplant: Can Contraception Reduce The Underclass?*””²⁵⁴ This was two days after the FDA approved the Norplant Contraceptive System. The sinister nature of the advancement of the administration of this contraceptive was that its target client base was African-American women and girls. Washington reports that between 1991-92 fifty thousand Norplant kits were inserted into the arms of predominantly African-American teenagers, ages 13-19, in the Baltimore public high schools. The first site for these implants was the Laurence G. Paguin Middle School in Baltimore in which 345 of the 350 girls implanted were African-American.²⁵⁵ These procedures, performed in school clinics were carried out without parental knowledge under the cover of confidentiality.²⁵⁶ As of 1990, all fifty states had integrated in their welfare programs through either a Medicaid reimbursement or a cash bonus.²⁵⁷ But Norplant contraindicates with African-American women among several morbidities including hypertension, diabetes, cardiovascular disease, clotting disorders and liver conditions. For all of these conditions African-American women have higher risks of death. With this knowledge one would think that removal of these implants would be supported financially just as the implanting itself. However, Medicaid reimbursements for removal were nearly impossible.²⁵⁸

In a 2002 study by Giselle Corbie-Smith, et al, their findings report that African-Americans were more likely to believe that physicians would not be forthright with them in discussing harmful research or any other associated risks or even treat them without consent.²⁵⁹

3.3.2.4 The Continuum of Health Disparities between African-Americans and Whites

The history of health disparities between African-Americans and Whites is as long as the history of African-Americans being in this country. As previously mentioned the living and working conditions of slaves were substandard creating environments where diseases could spread. Africans, like the Europeans, brought some diseases to this country with them, diseases that were prevalent in the regions of Africa such as malaria and hookworm. Smallpox and dysentery were brought to the shores of Africa from European slave traders where Africans were infected. Some were infected on the slave ships as they traveled the Atlantic to the Americas.²⁶⁰ Care for the children was a bigger concern on the plantations than for the adults because the children had to grow into working the fields.²⁶¹ In addition to smallpox and dysentery, many slaves were exposed to pleurisies, measles, whooping cough, and cholera and at times at epidemic proportions. What also contributed to their ill health was the non-nutritious diet commonly served.²⁶² Consequently mortality rates for African-Americans were higher than that for Whites.

Emancipation liberated slaves from chattel status but in many respects set them free to environments worse than from where they came. In addition, with segregation still entrenched within the American fabric, access to care for African-Americans was also substandard. In the North African-Americans were treated in segregated public hospitals

created and controlled by the local government whereas in the South Jim Crow laws kept separate facilities legal despite government subsidized care. African-American leaders, through the National Medical Association, pushed to create their own hospitals.²⁶³ Not only were patients disadvantaged but so also were African-American physicians. The American Medical Association (AMA) in 1947, through its appointed Commission on Hospital Care, noted that inadequate hospital facilities for African-Americans had two victims, the patient and the physician.²⁶⁴ Many of the segregated hospitals that were being built after World War II, particularly in the South, were built with federal money, due in part to the 1946 Hill-Burton Act that contained a “separate but equal clause.”²⁶⁵ African-Americans in the heavily populated South began migrating north and such a mass emigration created a strain on hospital facilities in the north redirecting attention from the discrimination laced South and heightening the awareness to the inequities in care in the North. African-Americans were forced to get care from African-American physicians. While that may seem fine, what was challenging was the patient to physician ratios. In Los Angeles in 1950 there were only 74 African-American physicians servicing an African-American population of 250,000. It was not uncommon during this time for hospitals to have explicit policies denying admission to African-American patients.²⁶⁶ Morais points out that the first sixty years of the twentieth century showed an improvement of life expectancy of African-Americans compared to the years of enslavement and the Reconstruction period despite evidence of discrimination. While some of this can be attributed to the advancing forces for civil rights, Morais states, “the irrepressible will of the Negro people to survive asserted itself.”²⁶⁷ By 1960, there was actually a narrowing of the health gap between African-Americans and Whites.²⁶⁸ When

the 1964 Civil Rights Act passed and with the introduction of Medicare and Medicaid in 1965 integration was mandated resulting in the closing of an extremely high number of African-American hospitals while others merged with white institutions. This left a damaging effect on African-American access care. In the 80s with the narrative now shifting to cost containment in healthcare managed care programs increased. By 1996 it was estimated that nearly two-thirds of African-Americans and Latinos were enrolled in managed care programs.²⁶⁹ A 2002 study by Cone, et al. reported that African-American patients were 1.5 times more likely to be denied authorizations under the managed care programs than white patients.²⁷⁰

In the twenty-first century, African-Americans still have the highest mortality and morbidity rates of any racial ethnic group, and between 1950 and 1998 African-Americans had the highest rate of death caused by cardiovascular disease, cerebrovascular disease, and malignant neoplasms.²⁷¹ In studies of emergency departments dispensing of analgesics it was reported that white patients were more likely to receive analgesics for pain than were African-American patients.^{272,273} Social, economic and psychological are important elements to consider when managing pain²⁷⁴ and African-Americans have historically been on the adverse side of the equation regarding the first two elements. In addition, under- and untreated chronic pain can eventuate in poorer health, quality of life and increased morbidity for African-Americans compared to Whites even when age, socioeconomic status and level of insurance are controlled.²⁷⁵ One must be aware of the fact that the disparities in healthcare for racial ethnics in general but more importantly for African-Americans are inextricably linked to a history tethered to race and class.²⁷⁶

These disparities have also been linked to physicians' perceptions of the patients. In a study by van Ryn and Burke results showed that physicians considered African-American patients as less intelligent than Whites, more likely to be noncompliant, have inadequate social support and more likely to be substance abusers compared to Whites.²⁷⁷ Therefore, any efforts to ameliorate the situation must be willing to eliminate the roots from which the disparities eventuate, specifically racism. When focusing on end of life and palliative care, the medical response to patients with chronic and terminal illness, a unified public health response for African-Americans is critical because health disparities for this population are evidenced from birth unto death irrespective of root causes.²⁷⁸

3.4 African-American Physicians, Medical Schools and Medical Societies

This section will examine the effects of racism and discrimination on African-American medical practitioners over the years, the role traditional Medical Schools played, the gaps filled by medical schools of historically black colleges and universities and the provisions of traditional and African-American medical societies amid the chronic condition of structural racism.

3.4.1 African-American Physicians Advancing Amid Adversity

The previous pages recount the horrific conditions of African-Americans over a three hundred year period in the slavery and Jim Crow riddled South, but also in the North. Throughout this history there were slaves and free "Negroes" who practiced medicine. As mentioned previously, slaves arrived in this country with their own understanding of sickness and corresponding remedies. It was holistic, relying on plants and spirits. It was considered superstition and voodoo to those who practiced Western

medicine. Because many slave owners felt that their slaves would feel more comfortable or have more faith in a “Negro” doctor they would sometimes summon for them. One story is told of a Virginia plantation owner named James Walker who sent one of his sick slaves, sick from poisoning, to see “old Man Docr. Lewiss.”[*sic*] Lewiss himself was a slave and the remedy he offered, “an herbal mixture, was helpful.”²⁷⁹ A slave by the name of Onesimus introduced a medical technique in 1721 that ended up saving the city of Boston from smallpox. Using the knowledge and experience he acquired in Africa, he shared with Cotton Mather, a scientist and Puritan preacher, this technique. It involved taking the pus from a person infected with the virus and planting it into the skin of a person uninfected. The uninfected person would be slightly symptomatic for a short while and then eventually immune.²⁸⁰ They were considered self-taught healers compared to those who apprenticed and others who studied in medical schools.

Those that were apprentices or educated in schools were primarily in the North but nonetheless because of prevailing discrimination they were few and far between. Dr. John S. Rock studied under Drs. Shaw and Gibbon but was rejected when he attempted to enter medical school in Philadelphia. Afterwards he studied dentistry and at the age of twenty-five opened his office. Later he was admitted to the American Medical College where he successfully completed his studies and began to practice medicine. When his health became a challenge he studied law and passed the bar in 1861.²⁸¹ Another noted apprentice is Martin R. Delaney who studied under three Pittsburgh doctors, Joseph P. Gazzan, Francis J. Lemoyne, and Andrew N. McDowell. Delaney, like Rock applied to medical school and like Rock was rejected because of his skin color. However his persistence carried him to Harvard Medical School and he was admitted in 1850. Delaney

did not finish but instead turned his attention to the abolitionist movement.²⁸² It wasn't until 1847 that an African-American would graduate from medical school. Prior to this professionally trained African-American physicians were awarded medical degrees from schools overseas, famously including, Dr. James McCune Smith who graduated from the University of Glasgow with his M.D. in 1837.²⁸³

3.4.1.1 Post-Civil War Reconstruction

At the beginning of this period, three years after the end of the Civil War and five years after the Emancipation Proclamation went into effect, two medical schools were established to assist in educating African-Americans – Meharry in Nashville, Tennessee and Howard in Washington D.C. Both faculty were held in high esteem; in fact, the Georgetown medical department considered Howard a serious rival because “the determination on the part of the ‘Niggers’ [*sic*] to be educated, and on the part of their friends throughout the North that they would be educated.”²⁸⁴ The distinction between Howard and Meharry was that Meharry's mission was strictly to educate African-Americans while Howard was open to Whites as well, male and female. Howard was in the forefront of racial equality and women's rights.²⁸⁵ Between 1865 and 1910 eight medical schools were established for the purpose of educating African-Americans.²⁸⁶

It has been reported that after Emancipation, former slaves found themselves living in conditions worse than when they were enslaved. As stated previously, the emancipated were out on their own struggling for food and other sustenance normally provided by the plantation owners, meager or not. As a result disease was rampant and death inevitable. The health disparity between Whites and African-Americans widened during the Reconstruction period. To assist the former slaves in adapting to life off of the

plantation the Freedman's Bureau was established in 1865, led by General O. O. Howard. He would become the founding president of Howard Medical School. Under his leadership the Freedman's Hospital was established in Washington D.C. and Dr. Charles B. Purvis, an African-American, was appointed surgeon-in-chief in 1881, the first African-American to head a hospital. He would later be summoned to the bedside of dying President James A. Garfield, the victim of an assassin's bullet. He was the only African-American doctor to serve a president of the United States.²⁸⁷ These subtle advances, however, would be met with adversity. Two members of the faculty of Howard Medical School, Dr. Alexander T. Augusta and Dr. Charles B. Purvis were recommended for admittance into the Medical Society of the District of Columbia. Both of these men were highly credentialed but apparently not credentialed enough. Both were rejected along with the application of Dr. A. W. Tucker.²⁸⁸ Despite the advocacy of Massachusetts senator Charles Sumner and Dr. Robert Reyburn, then surgeon-in-chief of Freedmen Hospital, the decision would remain unchanged. Even some white physicians were denied admittance on the basis of their support of the admission of African-American physicians.

The reaction of the Medical Society of the District of Columbia was not an isolated incident. As a result of this discrimination, African-Americans were forced to create their own medical society and in 1895 the National Medical Association was established. By 1912 there were over 500 members that included physicians, dentists and pharmacists.²⁸⁹ As a side note, African-American women were also denied admittance to nursing schools. As a result the Provident Hospital in Chicago was established for the purpose of educating African-American women desiring to enter the nursing profession.

There were some exceptions. Not long after Provident opened, the New England Hospital for Women and Children in Boston admitted African-Americans and graduated a half-dozen in 1899.²⁹⁰

3.4.1.2 Post-World War II

The National Medical Association (NMA) was the Negro equivalent to the American Medical Association (AMA). Established in 1847, during the first one hundred years of AMA's existence, African-Americans were still being excluded from membership. This was also the case for the county and state AMA affiliates in the South. This changed in 1948 when the Baltimore County Medical Society voted unanimously to include African-Americans in its membership. This action was followed soon after by the Oklahoma, Missouri, Florida and Delaware state medical associations.²⁹¹ Despite this developing integration on the state and county levels, several joint appeals on the part of white and African-American physicians to the national body to amend its constitution giving it the authority to prohibit affiliates from using race as the basis for membership exclusion fell short even as late as 1960.²⁹² The resistance to admit African-Americans was just as strong on specialty boards such as the American College of Surgeons. By the time the 60s started and as a result of mounting pressure from White colleagues, there were close to one hundred African-American surgeons as members.²⁹³ The nursing profession, however, moved on a different timetable. In 1946 the American Nurses Association (ANA) voted to admit all qualified nurses regardless of skin color and became the first profession in the country to integrate. Yet despite what appeared to be a success, income and opportunity inequality still persisted in the nursing profession.²⁹⁴

The situation with medical school education was similar as indicated earlier. After the Civil War, which marked the Reconstruction period, other than Meharry and Howard University medical colleges, there were thirteen other colleges in the North and South open to admitting African-Americans for study.²⁹⁵ The admission of African-Americans in traditionally white medical schools was very scant with the balance leaning more favorably in the North through much of the Reconstruction period. The Civil Rights Movement, at the end of World War II, included a push for racial equality within medical schools and medical societies. The reason was because twenty-six out of the twenty-eight approved medical colleges were in the South or states along the north/south border.²⁹⁶ It wasn't until after the significant civil rights advances through the Supreme Court decisions and federal legislation in the 50s and 60s that all medical schools began to open admission to African-Americans.²⁹⁷ Prior to the war by the 1930s internships for medical school graduates was becoming the standard and many African-American graduates were finding it difficult getting accepted. They were being excluded from white hospitals in the north and south but these students also found it difficult getting accepted in the all-Black hospitals as well obviously for reasons other than discrimination. A survey conducted between 1928 and 1934 discovered that only 60 percent of African-American medical school graduates were accepted into internships.²⁹⁸ But after the war and from the period of 1945-1960 more opportunities opened up for African-Americans to the extent that in 1956 there were more internship opportunities available than there were medical school graduates.²⁹⁹

In the late 60s and early 70s, after the 1964 Civil Rights Act, there developed an intentionality to improve the census of minority students in medical schools and their

representation in all other aspects of medicine. In 1969 the Association of American Medical Colleges established the Office of Minority Affairs and in the next year created the task force on minorities in medicine resulting in a couple of foci that became policy. One was the focus on those underrepresented in medicine whose representation is less than their percentage in the total United States population, and the second was to implement a parity goal in which the percentage in medical school and the population percentage were equalized. At that time African-Americans were 12 percent of the U.S. population yet a little more than 5 percent of the medical school enrollment.³⁰⁰

Petersdorf, et al. share in their research that the number of minorities, particularly African-Americans peaked in 1977 and has not reached that level of success since nor has it attained the goal of population parity. Also, from 1975 to 1989 while the minority population in the U.S. has seen an increase of 22 percent there was only a 12 percent increase in medical schools.³⁰¹

A snapshot in 1989 enrollment data revealed a reversal in trends from the 1970s in that a smaller percentage of minority students were accepted compared to the percentage of Whites. This is believed to be due partly to the shift in focus of the federal government according to the Graduate Medical Education National Advisory Council (GMENAC). The federal government declared a surplus of physicians in 1980 despite the GMENAC recommendation to continue targeting minorities and as the focus shifted so did the supporting programs. It is reported that by the end of the twentieth century the U.S. had the highest physician to population ratio in the world.³⁰² Peterdorf, et al. also attribute the decline in the minority candidates pool to the poor education system in the U.S. along with the high rate of poverty saturating many minority communities. In 1990,

minority students were twice as likely to not matriculate after admittance due to financial concerns.³⁰³ This is extremely true for African-Americans as they have been the racial ethnic minority group consistently hovering around the bottom of the social economic strata. In a recent report from the Association of American Medical Colleges, it was reported that even to date the number of African-American male applicants has not increased since 1978. Furthermore, the male to female ratio of applicants was lowest among African-Americans.³⁰⁴ One may wonder why there exists such an importance in diversity in medical school. One important reason is that while SAT and Medical College Admission Test (MCAT) scores may correlate to performance during matriculation they are not good indicators for forecasting successful residents or practicing physicians. An over reliance on these pre-matriculation qualifiers have produced physicians lacking in personal qualities when delivering care.³⁰⁵ Furthermore, better diversity among physicians correlates with greater access to care for low income and minority patients.³⁰⁶ Interestingly, scholars have noted that discrimination based on race and sex against medical school applicants was not limited to the United States but similar practices existed in England as well. A study by McManus, et al. revealed that of a cohort of medical school students in 1981 “applicants with non-European surnames were less likely to be accepted even after taking differences in academic qualifications into account.”³⁰⁷

This discussion on the shortage of minority candidates applying and gaining acceptance into medical schools should be held in tension with the increase in the number of immigrants to the U.S., particularly from third world countries. During the 1960s there was push by the U.S. for more third world immigrants to medical schools overlayed by

the changes caused by civil rights legislation to services rendered by hospitals benefiting the poor and elderly racial ethnic minorities. Prior to this point most of the international medical graduates (IMG) were primarily European.³⁰⁸ A significant number of IMGs are serving their residencies in teaching hospitals, which are primarily in urban areas. In New York City a study revealed that in the hospitals that reside in the poorest neighborhoods 70 percent of them are IMGs and only 24 percent of them are board certified compared to the citywide average of 64 percent. Furthermore, studies also reveal that physicians in the inner-city that accept Medicaid are more likely to be foreign and less likely to be board certified.³⁰⁹ The concern this information raises is the degree of familiarity or unfamiliarity IMGs have with knowledge of African-American history and culture. Most Whites in America are unaware of the journey of African-Americans in any detail and what knowledge they have is not at a depth to where they are able to understand the spiritual underpinnings that give rise to their perseverance and peace in the midst of pain and suffering. Even today white Americans still hold negative stereotypes towards minorities, particularly African-Americans, in large numbers despite the fact that only a few self-identify as being racists or bigots.³¹⁰ It is a narrow presupposition to posit that all minorities are able to provide the quality of care needed, particularly palliative care, to patients of another culture and ethnicity. Furthermore, research continues to show that a physician's association with or affiliation towards patients positively correlates with their objectivity both for young medical students³¹¹ and for experienced physicians.³¹²

3.5 Conclusion

Race and the construct of racial comparative frameworks have been around for hundreds of years. Along that history such comparative frameworks gave rise to a system ultimately called racism. Despite the many years of imperialistic practices in human history in which enslavement of foreigners was common, a particular European trajectory developed in which enslavement became not the bounty from military campaigns but the mechanism for human control based on skin color and the Africans were the longstanding objects. Ancient and noted theologians, philosophers and scientists developed principles, theories biblical interpretations based on flawed hypotheses masquerading as empirical evidence all to create a self-reflected superiority while relegating dark skinned people inferior, namely Africans. This gave rise to the Slave Trade, the vehicle for institutionalized slavery of Africans in America. What the Africans brought with them were the chains they did not want and the spirituality they refused to give up. This spirituality will be explored in more detail in the next chapter.

African traditional religion and practices helped the slaves forge an identity different from what slaveholders were trying to impart. The living and working conditions that slaves were subjected to were extremely unsanitary which led to a variety of illnesses and diseases. Medical care for slaves was wanting and inconsistent. Some slaveholders held the thought that a healthy slave was a good investment while others held the position that every slave was replaceable and deserving of the harshest of treatment. Because slavery was important to the southern economy efforts were made to sustain slavery through various laws. While a disproportionately number of slaves were in the South the North was not exonerated from culpability. The difference is that slaves

in the North fared only slightly better than those in the South. The Civil War marked a turning point in this country in that people were willing to fight over the issue of slavery, not because it was wrong but because it was dividing a country. Following the war the emancipated slaves found living and working conditions just as difficult afterwards as they were during slavery.

The Reconstruction Period after the Civil War launched the beginning of Jim Crow, a period in which more legislation was passed in southern states to further disenfranchise African-Americans, which lasted long after Reconstruction ended in 1877. African-Americans pushed for equality in all facets of life against the opposing tide of segregation and discrimination. Segregation and discrimination caused many African-Americans in the South to migrate north in search of better opportunities for work but those African-Americans were faced with a different form of discrimination. While the job opportunities were better than they were in the South African-Americans were still subjugated to the lowest socioeconomic status as they competed with European immigrants for housing and jobs. Still not advancing the socioeconomic disparities continued to promulgate health disparities between African-Americans and whites in morbidity and mortality rates. Because of this segregation, many hospitals would not treat African-American patients and those that offered substandard care. African-Americans were denied admission into many medical schools so they established their own. They were denied access to medical societies so they established their own. When civil rights measures forced integration and prohibited discrimination opportunities began to open for African-Americans but not in equal measure and despite these advancing opportunities

there was no amelioration of the socioeconomic or health disparities and even today African-Americans lead in most morbidity and mortality tables.

In conclusion, the history and continued challenge of oppression for African-Americans, which many would argue has undermined their human dignity. African-Americans have been and continue to be the disproportionate face of poverty throughout their history in the United States and as a result have suffered physically, emotionally and mentally. The projected outcome has been poor health and unjustified poor healthcare. David Wendell Moller, in his book "Dancing With Broken Bones," states, "the crowning indignity of a life lived in poverty about which no one cares is a death died in poverty while the culture smiles in indifference."³¹³ As we consider all of the struggles of African-Americans across the four hundred plus years of living, working and existing as residents in this country, one cannot ignore the spiritual energy that has driven the will of this people to survive and overcome. In the next chapter we will look at the genesis of such spirituality.

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- ²⁹ Isaac, "Racism: A Rationalization of Prejudice in Greece and Rome," 34.
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- ³¹ David Goldenberg, "Racism, Color Symbolism, and Color Prejudice," in *The Origins of Racism in the West*, ed. Miriam Eliasz-Feldon, et al. (New York: Cambridge University Press, 2009), 90.
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Chapter 4. Spirituality and Religion in Healthcare

Spirituality and religion are often conflated and used synonymously but over the years the two terms have become distinctly defined. Spirituality, religion in healthcare has been studied extensively over the years with the the goal of trying to understand how this construct effects patient decision-making and post-operative recovery as well has how they are resourced for strength in coping through life's difficult situations. This is of particular importance in the area of palliative care as part of the treatment modality includes addressing the spiritual as well as health deficits of patients with terminal illness. Where there are no spiritual deficits, spirituality may serve as a source of strength for these patients. For African-Americans their history of struggle and the evidence of endurance have long been attributed to the reliance on their faith. This chapter will explore the development of the distinctive defining of spirituality and religion, their influence within healthcare and how the nuance of African-American spirituality and culture uniquely locates within patient care.

4.1 Defining Spirituality

The obligation of physicians to relieve human suffering has been well understood for centuries but according to Dr. Eric J. Cassell, Clinical Professor of Public Health of Weill Medical College at Cornell University the idea of suffering has been neglected in medical education, research and practice.¹ Cassell also believes this silence or absence is due to the challenges within the practice of medicine of dichotomizing mind and body.² This indeed is a common goal of physician and patient. Yet as the body suffers from a decimating disease, so also it suffers at times from the treatment to rid the body of the

disease at the hands of the physician. Cassell further shares how he learned that his colleagues, through conversations with them, knew little and even had little thought about the subject of patient suffering, while medical students failed to see the relevance to their work.³ Healing is a term often referenced in the lexicon of spirituality and religiosity yet, according to Egnew, has “faded from medical attention and is rarely discussed in medical literature.”⁴ While physicians labor in pursuit of a cure, patients through spirituality and religion anticipate healing. Egnew continues, in referencing a definition provided by Dossey, et al, healing is “the process of bringing together the aspects of one’s self, body-mind-spirit, at deeper levels of inner knowing, leading towards integration and balance of each aspect having equal importance and value.”⁵ With this definition we see the intersection with spirituality when juxtaposed with Hardwig’s use of the term spiritual to mean the “concerns about the ultimate meaning and values in life,” as cited by Puchalski.⁶

As palliative care distinguishes itself from other care models by serving as a treatment modality for the mitigation if not alleviation of patient suffering, it is believed that suffering is also a spiritual phenomenon because it invokes within the person an inquiry for meaning and purpose.⁷ Within the context of palliative care, spirituality is an important component in the delivery of care to those with chronic and life threatening illnesses. It is therefore important for the sake of providing quality palliative care that there be a sense of clarity around what is meant by spirituality. Suffering, according to Eriksson, “is a mystery; it eludes human comprehension.”⁸ She continues by stating that a human being’s ability to suffer is formative in human development.⁹ In the previous chapter on race and health and the effects on African-Americans we reviewed a horrific

history of abuse. Applying Eriksson's point would suggest that the suffering faced by African-Americans over the course of their history forged the resiliency from which they were able to bend but not break. Spirituality is the instrument that enables humans to foster the ability to reconcile meaning and purpose amid suffering. As will be discussed later, in the context of care, medical professionals have to be able recognize and engage in this journey with the patient in ways that do not discriminate and devalue the patient's spirituality even though it may not accord with his or her own. Ivan Illich, as referenced by Cassell, suggests the concerns medical professionals have that are not directly related to the body fall into the realm of the spiritual.¹⁰ For Eriksson, nurses in particular should be able to address the demands and spiritual needs of patients despite the own incongruence with their own spirituality.¹¹

As evidenced in scholarly literature, spirituality is broadly defined in relation to religion or religiosity and will be defined in the same manner for the purpose of this work. While the focus in this chapter is strictly on Christian spirituality, spirituality is "transreligious" and is in vogue according to Barry Callen.¹² Spirituality over the previous decades has expanded in its meaning. Scholars such as Heelas and Woodhead would suggest that the feeling among several scholars is that this movement of growing spirituality in contrast to the declining influence of religion is perhaps the most significant event since the Protestant Reformation of the 16th century.¹³ The precursor of this view can be traced back to the period of antiquity when spirituality was contrasted against materialism, temporality and the corporeal things of life. Most recently in the 19th and 20th centuries the discipline of spiritual theology took shape with the focus on the Christian life and the striving for perfection. Recently, Catholicism included spiritual

theology among the variegated theological disciplines of dogmatic theology and moral theology, the substance of which focused on the non-obligatory.¹⁴ While moral theology focused on what Christians ought to do in obedience to the faith, spiritual theology addressed what we ought to be and how to get there as we saw briefly in Chapter two. Thus there was a renewed focus on the spiritual disciplines of prayer and meditation. As Muldoon and King state, spirituality came to refer to the “whole of Christian life and the whole life of the person which included the bodily, psychological, social, and political dimensions.”¹⁵

Scholars such as Sandra Schneider and Jean-Claude Breton have analyzed the approaches to applied spirituality and compartmentalized them into dogmatic and anthropological approaches. The dogmatic approach builds on the Catholic understanding of spirituality, which is a spirituality imputed by the Holy Spirit through grace, and is described as exclusively Christian. The limitation to this approach is that it is not ecumenical. It leaves no room for dialogue with people who do not share in this tradition. Conversely, the anthropological approach emerges from within a person and defines human life. It's that approach to spirituality where inquiry manifests, a longing for the divine resides, the pursuit of truth exists and where social belonging is recognized.¹⁶ This view of spirituality is more in line with what is defined in popular literature. Others have attempted to compartmentalize spirituality. Dr. Lance Christian Smith, Assistant Professor at the University of Vermont references the work of Heaton, Schmidt-Wilk and Travis where they have distinguished *true* spirituality from *applied* spirituality where the former is a “silent, unbounded inner experience of pure awareness devoid of cognition and affect while the latter is the “domain of measurable applications

and outcomes that arise from the inner experience of pure spirituality.”¹⁷ He further cites the work of P.F. Jankowski who divides spirituality into three different dimensions: cognitive, metaphysical and relational where the cognitive deals with existentialism, its beliefs and values, the metaphysical deals with experience of spiritual beyond human comprehension, and the relational focuses on relationship to the divine and associations with others.¹⁸ Callen, in quoting Sandra Schneiders, defines spirituality as, “the experience of continuously striving to integrate one’s life in terms, not of isolation and self-absorption, but of self-transcendence toward the ultimate value one perceives. For Callen, the ultimate value is God.”¹⁹

Dr. Lance Christian Smith cites how spirituality was defined in 1995 at the Summit on Spirituality by the Association for Spiritual, Ethical and Religious Values in Counseling. There spirituality was defined as,

“...the animating force in life, represented by such images as breath, wind, vigor, and courage. Spirituality is the infusion and drawing out of spirit in one's life. It is experienced as an active and passive process. Spirituality also is described as a capacity and tendency that is innate and unique to all persons. This spiritual tendency moves the individual towards knowledge, love, meaning, hope, transcendence, connectedness, and compassion. Spirituality includes one's capacity for creativity, growth, and the development of a values system. Spirituality encompasses the religions, spiritual, and transpersonal.”²⁰

Herein we see spirituality identified as a process one participates in as well as a capacity from within. Peter Hill suggests that because of such ambiguity in definition and distinction that research to this point has had limited value and perhaps it may be premature to insist on a “comprehensive definition” of either religion or spirituality.²¹ Hill, et al, resort to the work of Lawrence LaPierre who identified several components in this multidimensional framework. These components include: (1) a search for meaning,

(2) encountering the transcendent, (3) a sense of community, (4) a search for ultimate truth, (5) a respect for the mystery of creation and (6) a personal transformation.²²

In Chapter Two there was a brief discussion on the nature of spirituality and its definition. As was shared earlier, Washington and London define spirituality as “an inner search to find meaning and understanding of universal questions of human existence”²³ It also involves the recognition of our own finiteness and depending on our medical condition, our terminality. Consequently, three spiritual needs surface when treating patients in terminal stages of disease or illness, (1) the assurance that one has lived a meaningful life, (2) an appropriate death, and (3) the assurance of peace beyond death.²⁴ For Muldoon and King, spirituality is the “experimental integration of one’s life in terms of one’s ultimate values and meanings.”²⁵ Spirituality can include religion but is much broader in scope. This next section will review how scholars have thus far attempted to distinguish one from the other.

4.1.1 Differentiating Spirituality and Religion

While these concepts are important within the clinical environment scholars agree that defining spirituality and religion is difficult.²⁶ The two terms have often been used interchangeably and often inconsistently despite evolved distinctions in definition.^{27,28} In addition to this many scholars also suggest that the terms spirituality and religion are ambiguously defined.^{29,30} There has been increasing interest in spirituality and religion over the last few decades from the social scientific discipline³¹ and mental health professionals.³² In agreeing with the distinction that spirituality is broader than religion, Sulmasy offers that not everyone is religious but all are spiritual, even in the sense that

those who may reject the notion of a transcendent being whether or not they call the transcendent “God” are in relationship with the transcendent by their mere rejection.³³

Tracking the long road of scholarship within the academic field of psychology and social science, it has long been a study of religion and not a study of spirituality. Since the earlier writings of William James and G. Stanley Hall in the mid-19th to early 20th centuries, scholars have been interested in the psychology of religion and its effects on the health and well-being of people. Smith, in a review of literature on the subject of religion and spirituality tabulated the following characteristics of both. The following is his enumeration of the characteristics of spirituality: meaning, connectedness, transcendental/transcended, universal experience, subjective, purpose, compassion, inner wholeness, experiential, integrated, multidimensional, existential, hope, individual, internal experience, private, ecumenical, life enhancing, inner fulfillment, natural, limitless, and spontaneous. The characteristics of religion are: institutional, beliefs, organizational, denominational, system of belief/meaning, doctrine, external, explanation of the mystical, ritualistic, public, social, and tradition.³⁴ A comparison of these lists will reveal some overlap between the two terms. This should be of no surprise given the fact that there is etymological overlap as well. The word religion comes from the Latin root *religio*, which means a bond between humanity and a higher power while the word spirituality is from the Latin root *spiritus* meaning breath, and a person of the spirit would be *spiritulis* in the Latin.³⁵ One need also consider the Hebrew language of the Jewish text, in which *ruach*, denoted breath or spirit – the equivalent of spiritus. Its New Testament equivalent, originally translated into Greek used the word *pneuma* denoting spirit. The forgone conclusion from a Christian perspective is that a person of the spirit

must have a bond or relationship with a spiritual higher power. *Spiritus or pneuma* represents the essence of humanity while *religio* represents the relationship to the author, source or creator of that essence. Smith has also examined numerous sources and has found a collection of definitions for religion which include, an obligation to a particular organization or tradition of faith, the codification of spiritual experiences into a system, an integrated set of beliefs and activities, and lastly, a search for significance.³⁶ In the simplest of distinctions religion is pejoratively viewed as organized and spirituality is positively viewed as personal.³⁷

It cannot be understated that modern definitions of spirituality had their roots in religion. That is why there is overlap in the definitions with the broader perspective falling in the schema of spirituality. From a social scientific research perspective, research in religiousness has been conducted from two different approaches according to Zinnbauer, et al. They suggest that in the past the research into religion or religiousness has been from either a substantive or functional approach. The difference between the two is the substantive approach focuses on the relationship between individuals and a higher power along with the corresponding emotions, beliefs and practices while the functional approach focuses on the connectedness of these beliefs to life, death and suffering.³⁸ Smith examines earlier references to religion, in particular the scholarship of psychologist William James who at the turn of the 20th century viewed religion as linked to human sensibilities and feelings, something subjective and hardly measurable. He attributes this shift from the subjective to objective, and the ethereal to the tangible, to modernism where there was an increasing need to understand reality. Modernism is described by those who consider themselves postmodernists as the philosophical

movement out of early Europe consisting of theology, authoritarianism, racism, patriarchy, colonialism, domination and metaphysics, renowned thinkers such as Descartes, Hume, Rousseau, Adam Smith, Kant, Hegel and others.³⁹ Zinnbauer, et al, comment that the differentiation of spirituality and religion has led to the extraction, spirituality, of elements traditionally found in religion, thereby narrowing the focus of religion.⁴⁰ Smith, as he references the work of Sperry and Shafranske, shares three things that have caused the fissure between religion and spirituality which include, (1) individualism, personal autonomy and the critique of truth, (2) the decline of institutional authority and (3) exposure to other worldviews and beliefs.⁴¹ The critique of truth is a rejection of the absolutism projected from organized religion, namely Christianity. Concomitant to this is the negative stereotyping of religion and the positive connotations ascribed to spirituality. Hill, et al, track this separation to a rise in secularism, particularly the rise of science and “rational enlightenment over superstition and mysticism.”⁴² Claude Geffré, Professor Emeritus of Theology at the Catholic Institute in Paris, notes that secularization at one time was once a neutral term with a more juridical meaning referring to the transfer of church property to the State but has shifted to a connotation of emancipation from Church “guardianship” of human life and activity.⁴³ He further offers young people that guidelines for proper living are easily ascertained outside of religious life,⁴⁴ certainly endemic in the “baby-boomer” generation. It was during the 60s and 70s that the distinction between spirituality and religion began to take on more brilliance.⁴⁵ Zinnbauer, et al. report that according to a 1993 study by Roof of over 1500 baby-boomers a large number from this population during the 60s and 70s left organized religion for new “spiritual” experiences, many of them self-identifying as spiritual and

not religious.⁴⁶ Hill reports that while scholars such as Comte and Durkeim consider the religious shift to a more rationally motivated spirituality as social progress others such as Max Weber consider it an obstacle for people in search of meaning.⁴⁷ People considered religious are more likely to attend church, associate with high levels of authoritarianism and their parents most likely attended worship.⁴⁸ A profile of people who consider themselves spiritual and not religious reject organized religion and traditional forms of worship, highly educated, more individualistic and most likely came from homes where their parents attended worship services infrequently or were hurt by clergy.⁴⁹ What is important for the thesis of this work is that this search for meaning is quite operative for patients devastated by the prognosis of a life threatening illness.

There is extensive research that reports people self-identifying as spiritual not religious, or spiritual and religious. The Handbook of the Psychology of Religion and Spirituality reports that one in four people in the U.S. identify as “spiritual but not religious.”⁵⁰ However, there is little research that reports how study participants perceive the distinctions in the terms themselves.^{51,52} What Hill et al. report on a study performed by Sheridan, Bullis, Adcock, Berlin & Miller is particularly more disturbing in that in the context of palliative care is how less than 50 percent of licensed social workers, licensed professional counselors and psychologists believe that there is a God of transcendence and power. The same study also reports that less than 50 percent of clinical and counseling psychologists view religion as very or fairly important to them while over 70 percent note the importance of spirituality.⁵³ Why this may be problematic is that despite the professionalism of the field, harm can possibly be introduced due to transference or projection upon patients in need of their services given the importance of psychological

and emotional support for palliative care patients facing chronic and life threatening illnesses and family members of these patients. The likelihood may be higher among African-American patients given the reported prejudices stated in Chapter Three. As was also reported in Chapter Three, physicians offered better attention and care to patients they associate with. The associations included race and ethnicity. but what should also be considered is religion and spirituality and whether or not social workers, counselors and psychologists are also likely to provide better care to patients with whom they associate.

Hill remarks that the term spirituality is substituted in ways that leads to definitional distortion because the object of the reference is devoid of the sacred. In other words such distortions happen when spirituality is used in reference to ideologies and lifestyles independent of the sacred.⁵⁴ This sacredness is what has been institutionalized in religion. Another dimension that can be considered a distortion of the use of the term is the secularized movement by transhumanists, due to advancements in biogenetics, to establish spirituality for what they call “posthumans.” Tirosh-Samuelson suggests that the cybergenetics movement, linking on to postmodernism has created a philosophical track to where the meaning of being human is being challenged.⁵⁵ Posthumanism, a term that first surfaced in the mid-1940s at cybernetics conferences in New York was intended to guide the imagination for what post-biological, post-Darwinian human development would look like, according to Tirosh-Samuelson.⁵⁶ One concern emanating from this trajectory is the effect the conversation around the question of the meaning of being human can have on the search for meaning as human. This is something that will need further researching.

The polarization of spirituality and religion creates a complexity equal to the complexity of the attempts of defining these two terms. What is important to note is that the aforementioned discoveries and efforts to qualify the distinctions of religion spirituality is primarily a western endeavor according to Smith, citing Nelson, Rosenfeld, Breitbart and Galietta.⁵⁷ As will be discussed later, African-American spirituality is based on a worldview that is similar to Eastern religions where there is a holistic view of humanity. Hill, citing Pargament, makes the point that dichotomizing religion and spirituality creates the problematic insinuations that religions are not interested in matters that are spiritual and for spirituality to be labeled good while religion bad is to deny the research that has identified the positive and negative contributions of both.⁵⁸ Zinnbauer and Pargament offer that the labeling of these constructs as good or bad also “severely limits psychological inquiry and may reflect simple prejudice rather than informed analysis.”⁵⁹

Oman, cites a proposal from researcher and physician H.G. Koenig that two approaches to spirituality be employed, one for patient care and the other for research. He suggests that for patient care, the broadest definition possible of spirituality should be used so that the variant of patients can have their spiritual needs met and that for research purposes, the definition that returns spirituality to its origins of religion be used.⁶⁰ In contrast, physician Neil Scheurich opposes using spirituality when referring to meaning because etymologically it denotes the supernatural and non-corporeal.⁶¹

4.2 African-American Spirituality

In the third chapter of this work we examined the history of the delineation of race and its operative use as a way of oppressing Africans and African-Americans from

the transatlantic slave trade, the system of slavery and the morphological forms of subsequent oppression. What this section will discuss is how spirituality served as both the emollient for the weary souls and spirits of African-Americans as well as the agent that emboldened them for the journey. African-Americans had already discovered and were utilizing the benefit of spirituality and religion before spirituality became significant in the palliative care paradigm for alleviating patient suffering. As we have previously examined the bifurcation of spirituality and religion in an earlier section, it was reported that such an exercise was primarily a western phenomenon. Such a bifurcation is not prevalent with the spiritual practice of African-Americans and neither was its progenitor, African spirituality. In African religions there was and is no separation between the natural and supernatural, the human and the spiritual.⁶² The objective of the following section will be to trace the history and characteristics of African-American spirituality, often referred to as Black religion, and suggest it deserves greater attention and respect for how it should be more fully integrated into providing palliative care to African-American patients.

4.2.1 Historical Background

This section will in some degree mirror the chronological accounts developed in chapter three but from the perspective of how African-Americans engaged their spirituality as a means of coping with challenges beset them. This section will highlight two epic periods in African-American history – the establishment of the “Invisible Institution” and the establishment of the Black Church. To that end, one cannot apply African-American spirituality to healthcare related research without understanding how it arrived and how it developed.

African-derived religion is defined as that religion which originated in Africa but is practiced by African-Americans and there are some who when using this term only refer to those religions that maintained their originality.⁶³ In other words, such religions are still African religions just practiced by African-Americans. An example of which is the Yoruba Religion. The Yoruba religion originated in West Africa. It was carried to Latin America and the Caribbean during the slave trade and much of it ceased to exist during slavery except for on the island of Trinidad. Unlike other forms of African religions, Yoruba did not enter the United States until the 1960s.⁶⁴

Both Europeans and Americans who migrated to America from Europe at one time viewed African traditional religion as witchcraft, sorcery, pagan superstition and animism. During the Reformation, Protestants who traveled to West Africa were horrified by what they heard concerning the worship practices of the Africans, especially since they were fresh from repudiating what they considered idolatry in the Catholic Church.⁶⁵ According to Wilmore, European missionaries did a disservice to the integrity of the true nature of African religion when they labeled it ignorant and superstition. In addition, contrary to what missionaries may have believed, when the slaves arrived in the U.S., they had not completely given up their traditional belief system.⁶⁶ Some of the characteristics of this religion are that it maintains the belief in a Supreme Being, active in the daily lives of its adherents, with powers more supreme than any other. Although similar in some respects to Christianity, this Supreme Being was different in that the Supreme Being was approachable through various intermediaries.⁶⁷ In African traditional religion there is also no separation of the sacred and secular.⁶⁸ According to Luke Lungile Pato, “everyone who participates in the life of the community automatically participates

also in its religion.”⁶⁹ This concept of wholeness is the essence of the African worldview and is the cornerstone of the idea of being fully human. The idea of being fully human is not a given at birth but is developed through the interrelationships of family, clan, community and nation and through this association and process of socialization arises personhood and human dignity.⁷⁰ Pato continues by noting that in the African worldview, to be fully human means to belong and in quoting John Mbiti says, “I belong therefore I am.”⁷¹ This is a redirect of René Descartes’ saying, “I think therefore I am” which indicates African traditional religion’s incongruence with individualism and Modernity.^{72,73} An African saying that supports the relational nature of its worldview is “A person is a person through other persons,” the Xhosa reading *umuntu ngumuntu ngabantu*.⁷⁴

African-American spirituality is also communal, as is its progenitor, and is at the same time a response to what is perceived as radical evil in the community.⁷⁵ This radical evil has been defined as the tearing away of “African men, women and children from their homeland...lynching of black men and women, the sacrifice of children, and the destruction of families.”⁷⁶ Smith states, in quoting Peter Paris, African-American spirituality is an “amalgam of African meanings and Euro-American forms.”⁷⁷ For Young, African-American spirituality “signifies the inner strength that resists injustice, an inside vitality that aided by insight into one’s virtue and one’s oppressor’s vices, empowers one to reject a frustrating double standard.”⁷⁸ Its complexity does not allow for it to be defined in accordance with Catholic and Protestant paradigms because to do so would give too them too much credit for its development. As James Cone remarks, “Since we did not create the various Catholic and Protestant structures, we cannot use these labels as the

primary definition of our religious experience.” William James Jennings further adds this complexity is due to the fact that the formation of African-American spirituality was affected by Western Christian spirituality, the bi-locational workings of Christianity in Africa and America as well as the authentic African identity.⁷⁹ In the following sections more of its historical underpinnings and existential applications will be examined.

4.2.1.1 African Religion in Antebellum Slavery

Most of the African slaves came from West and West Central Africa representing Senegambia, Congo-Angola, the Bay of Benin and Nigeria and they came with mixed languages, cultures and religious traditions. Many from the Senegambia region practiced Islam and the Portuguese had spread Christianity in the Congo in the sixteenth century.⁸⁰ When they arrived in America they were stripped of their distinctiveness and viewed as a homogenous group of Africans. Some of the slaves brought to America were Christian but most of them practiced either Islam or practiced a form of African traditional religion. Christianity did not really develop much traction among the slaves until after 1830⁸¹ and by then most if not all the slaves were American born. Therefore the cultural and linguistic barriers were no longer a hindrance.⁸² As a point of note, it will not be the purpose of this thesis to follow the development and affects of slavery on those who practiced Islam or the effect Islam had on them. The focus will be primarily on Christianity.

What was common among the slaves was the foundation of their African traditional religion, which was highly ritualistic. It was common practice to believe in the supernatural powers of their ancestors and their role as protectors in their daily life.⁸³ While the expansion of Christianity into the continent of Africa traces back to the Middle

Ages it is important to note the similarities between the Catholic faith and African traditional religion. In particular, African ancestry worship was not dissimilar to the Catholic tradition of praying to patron saints, believing they too had the power of intercession e.g. St. George and St. James.⁸⁴ Parenthetically, when the Portuguese invaded the west coast of Africa these were the saints they called on in their war cries. When the slaves were brought to America there was a sense of justification on the part of European and European-American Christians for conquering Native Americans and subjecting them to forced labor and the same was true eventually for African slaves. The mission was partly to spread the European religion and culture.⁸⁵ Raboteau shares how this plan was even aided by prominent Catholic priests, particularly, how Dominican friar Bartolomé de las Casas assisted in the emancipation of Native Americans in place of using African slaves by making a personal appeal to the Spanish monarchy because the enslavement of Africans was considered a just war.⁸⁶

Slaves in the territories owned by Spain and Portugal noticed similarities between Catholicism and their traditional religion. For example, the Catholic saints were correlated with the African spirits and gods. Also, Mary, the mother of God, wearing blue and white, and the baby Jesus, were correlated with the Yoruba god, Yemanjá whose colors were also blue and white and was the patron god of childbirth.⁸⁷ As was the case with Catholicism so it was with Protestant religions that slaves made their necessary adjustments from within the framework of their own belief system. There was something amiss between what they heard in the Gospel and what they experienced. Wilmore suggests Christianity alone was not capable of providing the slaves all that they needed to develop the fortitude to resist and persist through the atrocities of slavery; therefore, slave

Christianity was enriched by the components of their African traditional religion.⁸⁸ This religion was fluid or adaptable, according to Raboteau, which allowed the slaves to adapt to Catholic or Protestant religions, their rituals and forms without losing their identity.⁸⁹ In the early 18th century, England, concerned about the lack of religious activities, the Quakers and Catholics in their colonies established the Society for the Propagation of the Gospel in Foreign Parts in which Anglican clergy, religious materials and other religious workers were sent to expand the reach of the Church of England.⁹⁰ In addition to the concern there was also a thought that if Christian values were taught to the slaves they would be more controlled and less apt to rebel. To that end Protestant clergy would proof text and erroneously translate scriptures. For example Ephesians 6:1 where the Apostle Paul offers the words, “Children obey your parents in the Lord for this is just,” it was changed to read “Slaves obey your masters...”⁹¹ But not everyone agreed with the plan to Christianize the slaves. There were some among British Americans who felt that it was illegal to hold a fellow Christian in bondage on the one hand and on the other felt that if slaves were baptized and then instructed in the Christian faith this would then enlighten the slaves to believe they were equal to whites and possibly fuel a rebellion.⁹² In response to the concern, here is an oath slaves were required to swear to as part of their baptismal vow:

“You declare in presence of God and before this Congregation that you do not ask for the holy baptism out of any design to free yourself from the Duty and Obedience that you owe to your Master while you live, but merely for the good of your soul and to partake of Graces and Blessings promised to the members of the Church of Jesus Christ.”⁹³

Accepting Christianity was very difficult for some slaves because they recognized the obvious double standard while others accepted it in hopes that it would eventually lead to their freedom.

Eighteenth century revivalism was very instrumental in the converting of slaves to Christianity. The reason behind this was how the expressive Pentecostal-like experience resembled their African traditional religion. This was also known as the Great Awakening. The Methodists and Baptists were the predominant representatives. The result of which led to increasing numbers of slave converts to the point where blacks outnumbered whites in some churches.⁹⁴ But this effort, while transformative for some slaves was also met with suspicion. Baptist and Methodists began challenging the legitimacy of slavery as part of living out the Gospel, condemning their ministers and members for their involvement in slave ownership as well as the buying and selling thereof. But when opposing pressure mounted from the South due to the economic ramifications from such a stance of the church, what was once an ecclesial edict receded to a more neutral position. The call for emancipation resolved into a call for fair treatment of slaves.⁹⁵ But while this was certainly the reality among slaves, the effect of Christianity would not be deterred and with this wave of evangelism many slaves attended segregated churches.

For slaves that could not attend churches, primarily in the South, the desire to gather was undeterred and from this fervor arose the “Invisible Institution,” named such because of the necessity to remain underground and out of sight of slave masters. These religious meetings of slaves became the incubator from which Biblical interpretation developed through the lens of the experience of slavery and in response to their

situation.^{96,97} There was such an unction among the slaves at these meetings that according to Raboteau, there was no need for a preacher because everyone was anxious to share a word. These meetings were also known as prayer meetings or “hush harbor meetings.”⁹⁸ At these meetings, in the words of a former slave, “the slave forgets all his sufferings, except to remind others of the trials during the past week, exclaiming, ‘Thank God, I shall not live here always!’”⁹⁹ There were some masters who would not allow their slaves to attend “meetings” either because they didn’t think “Negroes” had souls or for the sake of using it as punishment. Other slaveholders required their slaves to go to church on Sundays at the local white church or at services on the plantations that were conducted by either slave preachers or white ministers.¹⁰⁰ Slaves were not limiting themselves to Sunday gatherings either but would gather informally on weeknights in slave cabins.¹⁰¹ Slave religion, or African-American spirituality, during this time, according to Wilmore, was about mental and physical survival and so the slaves would interpret their situation and communicate hope to one another in the singing of the “spirituals” which on the one hand seemed to be litanies of gloom and sorrow but on the other hand were the means of being nourished.^{102,103} The spirituals were an example of a communal product. They were formulated from familiar African tunes blended with scriptural interpretation and improvisation.¹⁰⁴ The slaves would often sing and dance late into the night or all night some times and in order to keep from being heard by their master they would take the wash pots or the iron cooking pots and turn them upside down on the ground in order to keep being heard on the outside.¹⁰⁵ It was through the spirituals that slaves concentrated on their relationship with God in code language undecipherable to their masters due to the ethereal and otherworldly connotations. As Pinn states, while

trying to control when, how and where the slaves worshiped, if at all, slaveholders could not monitor the “musical articulation of an African worldview.”¹⁰⁶ But also evident in these songs was a theology that enabled the slaves to make sense of their enslavement¹⁰⁷ without embracing it. These spirituals resembled the songs, proverbs and tales of Africa where they served a dual function. They not only were used to promote communal values and invoke solidarity but also allowed for the occasional moments of transcendence above and beyond circumstances.¹⁰⁸ Levine adds, these spirituals “extended the boundaries of [the slaves’] restrictive universe backward until it fused with the world of the Old Testament, and upward until it became one with the world beyond [to God].”¹⁰⁹ There was also a deep longing for the suffering Savior, Jesus Christ. Christ was an example of right or proper conduct and through His suffering there was the hope of redemption and ultimate reward in heaven for their suffering. This is evident in the following stanzas.¹¹⁰

*Steal away, steal away, steal away to Jesus
Steal away, steal away home,
I ain't got long to stay here.*

or,

*Sooner-a-will be done with the trouble of this world,
the trouble of this world, the trouble of this world.
Sooner-a-will be done with the trouble of this world,
Going home to live with God.*

A certain theology was emanating from these songs and these songs were creating a particular theology that added to the complexity of African-American religion. This theology was one of liberation, perseverance, and trust in a God that is powerful, loving, compassionate, just and righteous.¹¹¹ It is important to recognize the location of trust for

surely it was obvious whom the slaves did not trust. This theology became the foundation for “Black religion” and Black theology, a theology of suffering within a religious framework. Slaves were able to develop a sense of independence as Black preachers began establishing their own congregations in the late 18th century and the numbers grew even more after emancipation because they gave concrete affirmation to what had been long hoped for. What was once an invisible institution was now visible and what was once a denial of choice evolved into a freedom to choose.¹¹² The invisible institution became the visible institution. In January 1788 the First African Baptist Church was established and Andrew Bryan was ordained to become its founding pastor. This independence came with a price. Bryan and others were forcibly dispersed, whipped in public, arrested and displaced. But this further emboldened Bryan and others for they thought that for them to have suffered such atrocities in the name of Jesus at the hands of whites then the Gospel must hold something significant that could be liberating for Blacks.¹¹³

4.2.2 African-American Spirituality in the 20th Century

4.2.2.1 The Role of the Black Church

The rise of the independent Black Church, and along with it Black theology and Black religion was put into service in other ways. As indicated in the previous chapter, after the emancipation of slaves other forms of discrimination developed heaping new burdens on African-Americans trying to establish personhood amid freedom. As was the case when slaves returned home from fighting in the Civil War, African-Americans who fought in World War I returned home from a battlefield where they were treated as equals

only to again be treated unequally. In the South African-American soldiers were beaten by whites and stripped of their uniforms. This in addition to the natural disaster of boll weevils destroying cotton fields and wrecking the economy led to what is considered the “Great Migration.” By 1930 more than 2.5 million African-Americans left the south and migrated north for better opportunities.¹¹⁴ This massive infusion of African-Americans in urban cities such as Detroit, Chicago, Cleveland and Pittsburgh caused racial tensions as migrants and whites competed for jobs and places to live. African-Americans were the last hired and first fired. When white workers went on strike African-American workers were brought in as replacements, which added to the tension.¹¹⁵ This migration led to the overcrowding of many churches resulting in expansion projects but more importantly, this led to the Black church substituting as social service agencies functioning as employment center and day-care centers.¹¹⁶ The millions that migrated from the South were looking for a place that would affirm their values and where community existed.¹¹⁷ Without the aid of the federal government, African-Americans continued to rely on their faith to help them navigate through the segregationist period of Jim Crow. All the force of Jim Crow was designed to tear the fabric of the African-American family as well as the community and so it was the Black Church that held things together.¹¹⁸ As Higginbotham notes, it was E. Franklin Frazier who called the black church a “nation within a nation.”¹¹⁹ In these earlier attempts to organize against white oppression it was the National Baptist Convention that was most significantly involved given its membership of over 2 million people as early as 1906.¹²⁰

The Black Church also became the center for protests. This was important because it marked a shift in African-American spirituality from an internal striving and a

hope in God's delivering power to that coupled with collective mobilization. This was faith in action. In the North as employment opportunities became a challenge amid discriminatory practices churches organized boycotts such as the "Don't buy where you can't work" campaign in Harlem during the 1930s.¹²¹ In a display of interdenominational unity, a national coalition of African-American Christians formed. It was called the Fraternal Council of Negro Churches. One of the driving forces for the creation of this organization was the disgust of African-American clergy who participated in the Federal Council of Churches.¹²² As an interdenominational assembly of predominantly white Church leaders, their refusal to address concerns of African-Americans such as supporting anti-lynching legislation as well as condemning the Ku Klux Klan is what angered the minority faction of African-Americans.¹²³ The Fraternal Council of Negro Churches consisted of the following denominations: the National Baptist Convention U.S.A., the National Baptist Convention of America, the African Methodist Episcopal Church, the African Methodist Episcopal Zion Church, the Christian Methodist Episcopal Church, the Union Methodist Episcopal Church, as well as African-American representatives from the Methodist Church and Congregational Church. Smaller black church denominations were also invited such as those identified as Pentecostal. The mission was the promotion of unity among the African-American churches as well as a unified effort of social action toward obtaining racial justice.¹²⁴ As Raboteau states, "despite their doctrinal differences, black Christians shared more with each other than they did with white Christians of the same denominations."¹²⁵ The reticence of white Christians also caused many African-Americans to spurn Christianity and join Islam and the Black Jews.¹²⁶ For them, Christianity was viewed as the religion of the oppressor.¹²⁷

Some African-Americans converted to orthodox forms of Judaism.¹²⁸ The trajectory of these faiths, their reaction to the oppressive era, and how this form of spirituality is executed in a healthcare paradigm is worthy of further research.

Another phenomenon that invoked contention within the Christian faith was that of the Social Gospel movement. Noted members such as Walter Rauschenbush, Josiah Strong and Washington Gladden among others in the movement made the conscious choice to address poverty rather than address racism in America. To add insult to injury, Gladden made the point that African-American progress is predicated on their ability to make cultural and psychological adjustments to meet the standards of the white majority.¹²⁹ This was interpreted that African-Americans were at fault for their continued state of disenfranchisement. The Great Depression created a pause point for much of the black church slowing the progress of activism. It was a matter of survival especially for those who had very little to begin with. As Pinn describes, black churches turned inward and became “de-radicalized” and in doing so advocacy and activism continued under the NAACP.¹³⁰ But not all were silent during this time. Reverend Reverdy Cassius Ransom, an itinerant AME minister found a place from which to perch and challenge the racist position of the “social gospelers” inferring that the proper proclamation of the social gospel is one that confronts the difficult issues on race rather than avoiding them.¹³¹

As the Civil Rights Movement got underway in the mid-20th century, the Black Church was again significantly involved. Propelled by the faith and activism of those that had come beforehand, clergy scholars such as Dr. Benjamin Mays, Howard Thurman and eventually Dr. Martin Luther King Jr. King’s background in philosophy and religion, coupled with the influence of Henry David Thoreau’s work “On the Duty of Civil

Disobedience” prepared Dr. King to lead African-Americans in civil rights campaigns such as Montgomery’s bus boycott, a campaign against transportation segregation and the sanitation worker’s strike in Memphis. When African-Americans saw this form of clergy leadership, exemplifying putting faith into action, it was energizing. The capstone passages of the Civil Rights and Voting Rights Acts of 1964 and 1965 respectively further conveyed to African-Americans that undeterred faith in God along with the resilient pursuit of justice could result in positive outcomes even against unfavorable odds.

4.2.2.2 The Christian Faith in the 21st Century

After having reviewed the significant history that gave rise to what is African-American spirituality today, one can see that it is not a spirituality, which focuses on private or individual reflection or monastic meditation, but is instead communal and progressive. African-American spirituality developed within communal struggle and situational strife, which in turn fortified a people along the way, by creating a pathway to freedom from bondage.¹³² It continues to be grounded in the history of African-Americans and focused on how to reconcile persistent struggle and undeserved suffering while in relationship with an all-powerful God.¹³³ That is why African-Americans cannot just detach themselves from the history of slavery the way Jack Kelly, staff writer for the Pittsburgh Post-Gazette would suggest. In an opinion piece Kelly remarked, “Slavery was horrible, but no black American living today has suffered from it. Most are better off than if their ancestors had remained in Africa. The black community is uniquely troubled, in large part because white racism is blamed for social dysfunction that has other causes. To address those causes, white Americans must abandon an undeserved guilt, and black

racists who blame all their problems on white racism must stop preying upon it.”¹³⁴ In contrast, modern day evidence of the historicity, progressiveness, and contextualization amid struggle of African-American spirituality is the sermon preached by Rev. Dr. Jeremiah Wright viewed by many right-wing whites as vitriolic and unnecessary to the point that the Senator Barack Obama, then a member of Dr. Wright’s church, made the decision to distance himself from Dr. Wright due to the court of public opinion. But Dr. Wright was executing the typical art form of “Black” preaching, a rhetoric involving an exegesis of the current conditions of African-Americans against its history and infused with the faith in a God who frees from bondage. That is why the Black Church can respond to events like the death of Michael Brown ¹³⁵ in Ferguson, MO, Eric Garner¹³⁶ in Staten Island, NY, or Sandra Bland in Bullock, TX after a routine traffic stop with outrage because its spirituality calls for it. This quote from W. E. B. Du Bois, as cited by Young, speaks to the historic and present perspective on the reality for African-Americans. Du Bois says,

“After the Egyptian and Indian, the Greek and the Roman, the Teuton and Mongolian, the Negro is a sort of seventh son, born with a veil, and gifted with second-sight in this American world, - a world which yields him no true self-consciousness, but only lets him see himself through the revelation of the other world. It is a peculiar sensation, this double-consciousness, this sense of measuring one’s soul by the tape of a world that looks on in amused contempt and pity. One ever feels his twoness – an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body; whose dogged strength alone keeps it from being torn asunder.”¹³⁷

Anthony Pinn, reflecting on the work of Franz Fanon, intimates that the long and tenured history of objectification resulted in African-Americans present inability to “transcend” their situations and circumstances and therefore “remained overdetermined or fixed in an historical time and space.”¹³⁸ This is not reflection of an innate inability of African-

Americans but a deprivation on the part of the overarching superiority of the majority culture. He further remarks, in the view of whites, due to their tenured history of superiority, African-Americans have “no culture, no civilization and no historical past.”¹³⁹ It would be unfair and untrue to say this quote applies unilaterally to all African-Americans today for there are likely some who would deny the gravity of this claim and would hold to the thought that many of the social ills today, by which African-Americans are victimized, are self-inflicted.

It is important to note that some African-Americans who are inflicted with a life-threatening illness, and who express the importance of their spirituality are not doing so with only the illness in mind. The illness is just part of a litany of sufferings of various forms to which the patient was directly or indirectly affected. As Smith remarks, “the legacy of slavery that the evils of racism begat still continues as an entrenched and often ignored or denied feature in contemporary American society.”¹⁴⁰ As long as that continues to be the reality for African-Americans then their spirituality will continue to be one grounded in chronic and not acute suffering. When African-Americans sing Negro Spirituals today and the Negro National Anthem “Lift Every Voice and Sing,” it is done so knowing that they are not singing alone but are joined by the heavenly chorus of ancestors who paved a way before them amid struggle enforcing the fact that African-American spirituality can “transcend the status quo and historical memory can inspire hope.”¹⁴¹

4.3 Spirituality and Healthcare

Using the historical context developed in the previous section as backdrop this section will examine the engagement of spirituality within the medical environment from the perspective of the patient. Because many studies include both spirituality and religion in their research both will be included in this discussion. Additionally, the majority of study participants in research, which will be reviewed, self-identify as spiritual, religious, or spiritual and religious.

It has been well documented that the goals of patients and those of clinical practitioners are at times in misalignment often due to lack of adequate communications as was discussed in Chapter Two. Bruce Feldstein cites a quote from French physician Edward Livingston Trudeau where he states, ““to cure sometimes, to relieve often and to comfort always.””¹⁴² Spirituality and medicine have been in relationship for hundreds of years and originally symbiotically as clerics attended to the body and spirit. Even earlier hospitals were created through the work of religious societies.¹⁴³ Over the years there has been increasing interest in the effect of spirituality and religion in health outcomes especially in the late 20th century.^{144,145} Most of the increase has been focused in the area of spirituality and health as opposed to religion and health. Research in the fields of psychology and behavioral sciences have been increasingly studying the implications of religion/spirituality on health.^{146,147} In pondering the substantive relationship between spirituality and medicine Sulmasy offers several views. He suggests that as physicians are committed to the art of healing, which in essence means to make whole, then it is important for them to understand how disease affects the patient as a spiritual being with ontological questions.¹⁴⁸ Continuing his position Sulmasy references the 20th century

Jewish philosopher and theologian Abraham Herschel who stated that physicians must be serious in engaging ontological questions themselves if they are to be effective healers and also see medicine as a spiritual practice.¹⁴⁹ For Sulmasy, illness is a spiritual matter. It “grasps persons by the soul and by the body and disturbs them both.”¹⁵⁰ Scheurich finds the separation of medicine and spirituality mutually beneficial in respect of pluralism and because the term spirituality carries an inherent “bias in favor of supernatural beliefs” and that axiology would be more appropriate due to its values based meaning.¹⁵¹ What Scheurich fails to understand is that spirituality has evolved into such broadness in scope, unfortunately, that some has to wonder if even the supernatural is even being referenced. Axiology ends up being more exclusive than spirituality and it is up to the individual in this post-modern era to define for himself or herself if the transcendent is the object of reverence. Scheurich does not deny the point that spirituality can be defined in non-religious ways but further asserts the synonymous way in which spirituality and religion are used in literature thereby supporting his notion of a biased connotation for the affinity for the supernatural.¹⁵²

Scheurich’s apparent secular position fits the outcome described by Ghadirian of the battle between the religion and medical science to where from a physician’s perspective the emphasis is more on the disease and not on the person.¹⁵³ As Sulmasy reminds us, physicians must realize that patients are people and that they themselves are people too and that the interpersonal relations between a physician and patient is a spiritual interaction. He states, “the healing presence of the divine is to be found not only in explicitly religious conversations with the dying, but in all those countless moments in the office or the hospital in which we communicate meaning and value to our patients

and relate to them as persons.”¹⁵⁴ Medicine is inherently holistic. It is endowed with both science and spirituality, according to Ghadirian. As one looks at humanity it consists of inner and outer relational dimensions. The outer dimension focuses on how we relate one with another and our environment, while the inner is about our relationship with the transcendent. It is science that operates in the outer sphere while spirituality operates within the inner.¹⁵⁵ While the body is the object of medical treatment when illness and disease disrupt its entropic balance it also serves as the frame and capsule for the soul. Research has proven that disease and illness of the body have an effect on the person psychologically and also that psychological anomalies can negatively impact the body. For example there is psychobiological evidence that stress produces coronary artery disease (CAD) and hemostasis molecules.¹⁵⁶ Likewise studies have shown that illness and disease, particularly terminal, have a negative effect on patients psychologically. In fact, that is what led to the creation of palliative medicine through the discoveries of Cicely Saunders and her contemporaries. Therefore to treat the body and not the spirit and vice versa is incomplete care and an affront to the honor and dignity of the practice of medicine, those who practice, and perhaps most significantly to patients.

Medical science and the creative technological advances have led to a shift from a humanistic and natural approach through which healing takes place to a more technical and biochemical approach to where treatment is the focus. It has been posited that a continuation of this trend could lead to the dehumanization of medicine.¹⁵⁷ Sulmasy uses the term scientific reductionism, and views it as a threat to the conjoining of spirituality and the practice of medicine because of its denial of the transcendent.¹⁵⁸ In citing Kearney, Ghadirian suggests that one will find a distinction between treatment and

healing in the physician-patient relationship. She adds, "Treatment and cure reflect a physician's relationship with the disease and its eradication...healing is a process through which a physician relates to the patient and his [or her] *sic* personhood."¹⁵⁹

A study by Eisenberg and colleagues, which looked at the use of unconventional therapies, reflected on data from a sampling of over 1500 study participants, reported on the widespread use of unconventional therapies. These unconventional therapies were defined as medical interventions not widely taught in the US medical schools or rarely available in U.S. hospitals.¹⁶⁰ Examples include, acupuncture, chiropractic, massage, herbal medicine, spiritual healing, prayer, exercise, hypnosis, homeopathy, etc. The study measured the prevalence of use within the past 12 months. The 10 most reported medical conditions for which these therapies were used included, back problems, allergies, digestive problems, anxiety, depression, high blood pressure, sprains, strains, arthritis and insomnia. Among the findings, 25 percent used prayer and 26 percent used exercise. What is most important to note from these findings in relation to the thesis of this work is that the population that used unconventional therapies the least was African-Americans and people with incomes less than \$35,000 (1993 salary figures).¹⁶¹ The data also suggested that patients in the study who had multiple conditions were more likely to also see their medical doctor. While this study does not report this, it is reasonable to surmise that there may be a positive corollary between African-Americans with a number of medical conditions, which necessitates them seeing their medical doctor more often thus using unconventional therapies less.

4.3.1 Medical Professionals and the Provision Spiritual Care

Scheurich notes that it is generally believed that spirituality and religious belief are more prevalent among patients than among physicians further suggesting the need for physicians to be more engaged in matters of patient spirituality. But he further cautions an insistence on such attention may lead to unnecessary inflation of the role of physicians and could dilute the efficacy of medicine.¹⁶² In finding the term spirituality ambiguous, Scheurich suggests that medicine ought to remain spiritually neutral because the use of spirituality and religion in most of the scholarly literature conflate the terms, inject theological bias and risk alienating physicians who either adhere to minority faiths or are atheists or agnostics.¹⁶³ While avoiding spiritual matters may be the simplest and easiest solution for physicians it may not be the best.¹⁶⁴ The need for awareness of physicians who hold affinities to minority religions is important and as reported earlier, Koenig's suggestion of using a broad definition of spirituality should serve the purpose of being widely inclusive.

At a conference in 1996 of the American Academy of Family Physicians where 296 physicians attended, 99 percent expressed their support in the belief that faith and prayer positively influenced patient healing and recovery.¹⁶⁵ In another survey by Luckhaupt¹⁶⁶ et al, conducted in 2003 medical residents at a Midwestern medical school several outcomes were reported. These residents represented a cross-section from various medical disciplines including pediatrics, internal medicine, family medicine and internal medicine/pediatrics. In a respondent base of 227 residents, 46 percent felt that they should play a role in their patients' spiritual and lives while 90 percent felt awareness of patient spiritual and religious beliefs was sufficient. When tracked according to discipline

it was reported a larger percentage of those in family medicine, 74 percent agreed compared with only 33 percent of those in internal medicine. On the question of whether or not physicians should be aware of patients' spiritual and religious beliefs of the 90 percent who agreed 96 percent were in family medicine with 79 percent in internal medicine. Lastly, what was of great significance in relation to the basis of this thesis is the analytics on the question relating to whether or not spiritual and religious beliefs of the physician are important to patients was strongly associated by race. Fifty-six percent of African-Americans agreed that this is important to patients, while 27 percent of whites and 17 percent of Asians agreed.¹⁶⁷

Several studies have reported patients indicating their preference for conversations about their faith with their physicians and health care providers.^{168,169,170,171} In addition a 2002 report authored by Mansfield et al, according to Ghadirian, indicated that 80 percent of the 1033 study participants in the South believed that the cure of disease is an act of God working through physicians.¹⁷² A suggestion offered by Sulmasy for restoring the symbiosis between medicine and spirituality, or to facilitate the engagement of physicians with patients' spirituality is for physicians to take their own religion and spirituality seriously and secondly to find and converse with other physicians openly despite dissimilar beliefs, about spirituality and the needs patients often express.¹⁷³ Perhaps one of the more credible scholars in this conversation is Chaplain Bruce Feldstein, MD. Chaplain Feldstein spent 19 years as an emergency room physician before becoming a Jewish chaplain at the Stanford Medical Center. He shares how as a physician he would become overwhelmed with emotion when he had to tell a family that their loved one had died and he would seek out a nurse to spend time with them.

However, when Feldstein became a chaplain he realized he was now the one being called to be present with families or patients during moments of distress. In the classes he teaches with medical students and physicians he notes that he encourages medical students and physicians to share personal stories about their spiritual experience. In doing so the topic will often navigate through seemingly disparate experiences from scenic views in nature to moments in the operating room. Feldstein's point is that he wants them to understand they do not have to "deny their faith and spiritual values" while practicing medicine, something he had to learn as well.¹⁷⁴ He further adds, because the spiritual dimension of the healing process is often neglected in the practice of medicine that in the end it's the patient and health care providers that suffer.¹⁷⁵

4.3.1.1 Barriers to Providing Spiritual Care

4.3.1.1.1 Institutional Barriers

There are several institutional barriers preventing the adequate delivery of spiritual care to patients. In many health care systems across the country, for-profits in particular, there are efforts to increase efficiency, minimizing costs in order to maximize profits. Insurance companies operate off of the same economic model; therefore, their cost containment objective is to manage payments for treatments. This is understandable to a point, as health care costs have risen significantly over the years. However, if promoting efficiency includes incentivizing doctors with bonuses that increase as expenditures decrease then physicians are not able to direct their attention to the things that matter most to patients. According to the Center for Disease Control the personal health care expenditures in 2013 totaled \$2.5 trillion and hospital care was 38 percent of

that figure.¹⁷⁶ When managerial decisions are made to cut costs those reductions generally take place in the spiritual care departments particularly in large managed-care organizations.¹⁷⁷ In the middle of this economic decision are the patients. We noted earlier that managed care plans hamper the patient-physician relationship and one way in which this happens is by straining the obligation of physicians to be patient advocates as physicians find their loyalties in conflict. There is the concern of knowing what will be beneficial for a patient and not being able to order it or ordering treatment that will pay but will offer little benefit to the patient. This clearly is ethically problematic in both aspects. In addition, in a study by McCauley, et al, of managed care physicians, 95 percent of them reported that lack of time was one of the reasons they do not engage in discussing a patient's spiritual needs as physicians do not have the luxury of spending an indiscriminate amount of time with patients under a managed care system. Lack of training was one of the other reasons noted.¹⁷⁸ However, one of the things that leaves spiritual care near the top of the pecking order of things being cut or downsized in healthcare systems is the fact that it is not a revenue generator which leaves one to wonder if the priority of medicine is shifting from patients to profits or from care to costs.

Ghadirian cites an editorial by Nancy Andreasen where she states there is increasing pressure on physicians to address the body and neglect the mind and spirit and there is an insensitivity of health care systems to the psychological needs of patients.¹⁷⁹ Sulmasy refers to this as the industrialization of medicine because it denies the importance of spirituality from the outside of medical practice.¹⁸⁰

4.3.1.1.2 Attitudes of Physicians toward Spirituality and Medicine

Some scholars report that physicians feel a sense of uneasiness discussing spiritual or religious issues with patients as for them such discussions are outside of their expertise and “jurisdiction”.¹⁸¹ These jurisdictions or boundaries are setup formally and informally. According to Cadge, et al, the boundaries are setup formally through training, licensing, legal precedence and associations while the informal boundaries are established in everyday practice. Exceptions are sometimes made in what Cadge, et al cites and what Gieryn calls “boundary work.” This is described as negotiated decision making.¹⁸² In a survey of pediatricians conducted by Cadge and colleagues around the relevancy of religion and spirituality to the practice of medicine it was reported that more pediatric oncologists than pediatricians see the relevancy of religion and spirituality to their daily work. They also suggest that scholars who have a better understanding of the interaction of spirituality and religion with medicine are usually less concerned about whether or not patient care is impeded by this interaction. Furthermore, Cadge et al recommend more balanced research in order for the Joint Commission on Accreditation and Healthcare Organizations (JCAHO) to be better informed in outlining standards of care with regard to patient spirituality.¹⁸³ In offering an opposing position on the beneficence of integrating spirituality into the treatment model, Cadge et al posit that religion and spirituality is just as much a barrier as it is a bridge in offering patient care. Specifically, it can be a barrier in medical decision making when children cannot receive the care they need when the faith of the parents interfere with recommended care. Yet for some religion and spirituality are only seen as a bridge in end of life situations or when they can help answer questions medicine cannot.¹⁸⁴

Christina Puchalski agrees that in end of life situations physicians should be attentive to the spiritual needs of patients. She states, “We as caregivers need to engage with our patients on the same spiritual level” and “it should be a meaningful experience for dying persons, a time when they find meaning in their suffering and have various dimensions of their experience addressed by their caregivers.”¹⁸⁵ She further alludes to a statement from the Association of American Medical Colleges (AAMC) that reads, “Physicians must be compassionate and empathetic in caring for patients...they must act with integrity, honesty, respect for patients’ privacy and respect for the dignity of patients as persons. In all of their interactions with patients they must seek to understand the meaning of the patients’ stories in the context of the patients, and family and cultural values.”¹⁸⁶ Note that the AAMC, in their statement, is not limiting the need for compassion and empathy only in interactions with patients near death. Sometimes doing the right thing may not have a prescription associated with it. Perhaps doing the right thing, as Feldstein suggests, is doing what is really important for the patient and it may stretch the physician and healthcare professional beyond their defined roles and perhaps into the uncomfortable space of spirituality and personhood.¹⁸⁷

Again referencing the study by McCauley, et al on spiritual beliefs and barriers among managed care practitioners. In their study they noted 68 percent of their managed care physicians agreed that it is their responsibility to address spirituality concerns of patients is part of the physicians’ role. Forty-seven percent thought that patient spirituality should be routinely discussed as part of patient history and physical.¹⁸⁸ But while there are certainly those patients who express the desire of having spiritual conversation with their physicians, there are the minority of patients that do not believe it

is necessary. Ehman, et al, cite reports in which only a minority of their sampling welcomed conversations with their physicians about their spiritual beliefs and values.¹⁸⁹ Therefore what leads to the discomfort of many physicians is the knowledge or sense of when and with whom such engagements would be appropriate. Education is one way to help overcome personal barriers physicians and other healthcare professionals may have in managing the encounter with patients so that expressed spiritual needs of the patient can be addressed.¹⁹⁰ Some medical schools include in their instruction how physicians can conduct spiritual interviews.¹⁹¹

4.4 Positive and Negative Impacts of Spirituality on Medical Decision-making

As was reported earlier, Scheurich, Cadge and colleagues believe that spirituality and religion can create a barrier to medical decision-making. For the past 30 years there have been studies in medical and psychiatric journals that religion and spirituality have positive influences on health.¹⁹² It has also been reported that religion/spirituality help patients in coping with their conditions by providing comfort.¹⁹³ A study by Laura Phillips, et al, suggests that patient motivations for religious and spiritual involvement can have a positive or negative impact on mental health outcomes.¹⁹⁴ In a review of literature analyzing the effects of religious beliefs on the treatment preferences of African-Americans, Johnson et al noted that one study of women with breast cancer, African-American women were more likely to report receiving support from God whereas white women were more apt to report receiving support from the spouse or friends.¹⁹⁵

African-Americans are less likely to share their medical preferences in writing. There are a number of factors cited as reasons why this is the case such as a lack of

awareness or understanding of the importance of advance care planning, mistrust in the health care system, religious and cultural beliefs.¹⁹⁶ First and second generation studies support that African-Americans would prefer to share their preferences with family members rather than in a written directive.^{197,198}

In addressing the lack of awareness or understanding some of this points again to the preconceived perceptions of African-American patients and or cultural insensitivity on the part of the medical professional. Ryn and Burke point out in their study “physicians rated [African-American] patients as less intelligent than white patients, even when patient sex, age, income and education are controlled.”¹⁹⁹ This perception could lead to the assumption that African-American patients are not able to understand treatment options. Nonetheless, it is ethically imperative for medical professionals to inform and educate patients of their options in a manner in which a reasonable person would understand, unless their decision-making capacity is insufficient or the courts deem them incompetent and in these situations communications should be with a surrogate. However, due to the bias toward African-Americans on the part of some physicians, as previously mentioned, an interpretation of what is reasonable could be flawed. There is also a concern that medical professionals are not properly trained on how and when to have the discussion with patients on advance directives specifically or advance care planning in general. There is also the risk of misuse as well. Bergmen-Evans, et al. note that the responsibility on the part of the medical professional to initiate an advance directive discussion, follow-up, and educate is often vague and ignored and that there is also a tendency to narrowly use advance directives as simply DNR or CPR

orders.²⁰⁰ Knowledge of this can further intensify the mistrust of African-American patients further hampering the medical decision-making process.

The distrust of African-Americans, in general, in the health care system and incongruence with religious and cultural beliefs is an issue that has been decades if not centuries in the making. When discussing the mistrust factor many point to the significant and unfortunate Tuskegee experiment where African-American men were used as “guinea pigs” in a syphilis research study under manipulative pretenses. However, as was conveyed in a previous chapter, the seed of mistrust was planted much earlier in history. Within the domain of healthcare and medical decision-making, a form of mistrust is evident when you look at the perceptions of living wills and advance directives among African-Americans. Many African-Americans believe that they would be treated differently or would receive less care if they had a living will or advance directive.²⁰¹ But when the attitude of physicians toward end of life decision-making was analyzed based on race, age and gender, interesting results surfaced. Crawley and Payne cite research reported in 1999 by Mebane, et al. that found “58 percent of white physicians saw tube feeding of terminally ill patients as heroic, but only 28 percent of [African-American] physicians agreed, and [African-American] physicians were more than 6-times more likely to request CPR and mechanical ventilation for themselves when in a persistent vegetative state.”²⁰² Consistent with this finding is the observation reported by Johnson et al where they state, from their review of literature, African-American spirituality is believed to be causative of patient slow utilization of palliative care and desire for aggressive treatment such as cardio-pulmonary resuscitation and the use of mechanical ventilation.²⁰³

Some scholars have noted from their research that African-American patients perceive themselves to be of lesser value to medical professionals thereby resulting in a lesser level of quality of care.²⁰⁴ In addition, it was also noted in a study by Hansen et al that African-American patient preferences outside of traditional medical schemes was met with minimal support by medical personnel even though this preference accords with the cultural remnants of African traditional religion.²⁰⁵ For example studies have shown that African-Americans have used alternative remedies in treating anxiety and depression.²⁰⁶

Spirituality among African-Americans has been an important factor in how one views life and death. Illness and death can be viewed by African-Americans as just another element of pain and suffering along life's continuum there to be overcome through the testing of their faith, much like the pain and suffering found in the history of their ancestors. In the area of palliative care this perspective on faith or the nobility of suffering can create challenges in establishing treatment goals.²⁰⁷ Consistent with this tension is the reliance of some African-American patients on clergy who have no understanding or knowledge of the benefits of palliative and hospice care.²⁰⁸ While there are various models analyzing the role of religion and spirituality on healthcare outcomes and decision-making, Crawley et al suggest broader societal dialogues will be necessary to better understand the insufficient utilization of palliative care by African-Americans given the complex construct of the perceived values in spirituality and religion.²⁰⁹

4.5 Conclusion

In conclusion, spirituality and religion have been conflated in many studies over the years and even in normal parlance the two have been used interchangeably. But

spirituality is beginning to be defined over and against religion in ways that broadens it as a more inclusive domain. For many, spirituality includes religion but not the converse. It is believed by some that while not everyone is religious, all are spiritual, even atheists. As time has progressed studies have shown there are an increasing number of people self-reporting as spiritual and not religious. Some of the reasons attributed to this departure away from religion and towards spirituality are instances of spiritual injury or the presence of unwanted and restrictive organizational structures in religion. There has been a litany of studies analyzing the effects of the integration of spirituality and religion within the context of healthcare with most evidence demonstrating positive correlations. The examination of the spirituality and religion construct, in the context of healthcare, centers around the human aspect of suffering and how this construct finds utility in amelioration efforts. Some have viewed human suffering as formative in human development. Therefore the role of spirituality and religion is to hold in tension the pain associated with the suffering and the positive development that results.

African-American spirituality while broadly defined is also very religious in its practice, resulting in a complex and holistic construct. African-American spirituality was birthed in the struggles of American slavery but has its origins in African traditional religion and its practices. Its usefulness over the centuries has been fruitful and in turn has been developed in itself. African-American spirituality found its identity in the suffering of people with hope for redemption and a way to transcend the suffering; likewise, the people found their identity in the spirituality with its focus on overcoming hardship brought on externally. In regards to palliative care it is important to recognize the significance of spirituality and religion within the care protocol. With the goal of

palliative care being the alleviation of suffering it faces challenges in the African-American community in several ways. One such challenge entails the beneficial properties suffering has in the minds of some Christian African-Americans due to its alignment with the suffering of Christ and the resulting award for perseverance through suffering. The other challenge relates to the lack of access to palliative care services for some African-American patients or the lack of information about these services due to physician bias. How patients perceive their value to physicians and how patients perceive physicians value them can create tension in the patient-physician relationship and hinder the deliver of quality care. Several studies have revealed how physicians project a bias of inferiority onto African-American patients, which has led to inadequate pain management and insufficient communications. This further confirms and validates the mistrust African-Americans have long had and continue to have toward medical professionals. In order to deliver excellent palliative care to African-American patients it will be important to find ways to understand the patient holistically e.g. physically, spiritually and socially. The social aspect involves any sociological factors that may have contributed to ontological inquiries beyond the affliction of a chronic or terminal disease. One way of doing this is through spiritual histories and other assessment models, which will be examined in the next chapter.

¹ Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, 2nd ed. (New York: Oxford University Press, 2004), 29.

² Ibid. 31.

³ Ibid.

⁴ TR Egnew, "The Meaning of Healing: Transcending Suffering," *Ann Fam Med* 3, no. 3 (2005): 255.

⁵ Ibid. 256.

⁶ Puchalski, *A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying*, 11.

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- ⁷ Kenneth J. Doka and Amy S. Tucci, *Living with Grief: Spirituality and End-of-Life Care* (Washington, DC: Hospice Foundation of America, 2011), 3.
- ⁸ Katie Eriksson, "Caring, Spirituality and Suffering," in *Caring from the Heart: The Convergence of Caring and Spirituality*, ed. M. Simone Roach (New York: Paulist Press, 1997), 68.
- ⁹ Ibid. 74.
- ¹⁰ Cassell, *The Nature of Suffering and the Goals of Medicine*, 31.
- ¹¹ Eriksson, "Caring, Spirituality and Suffering," 71.
- ¹² Barry L. Callen, *Authentic Spirituality: Moving Beyond Mere Religion* (Lexington, KY: Emeth Press, 2001), 16.
- ¹³ Paul Heelas et al., *The Spiritual Revolution: Why Religion is Giving Way to Spirituality* (Malden, MA: Blackwell, 2005), 2.
- ¹⁴ Maureen Muldoon and Norman King, "Spirituality, Health Care, and Bioethics," *Journal of Religion and Health* 34, no. 4 (Winter 1995): 331.
- ¹⁵ Ibid. 332.
- ¹⁶ Ibid. 333.
- ¹⁷ LC Smith, "Conceptualizing Spirituality and Religion: Where We've Come from, Where we are, and Where we are Going," *Journal of Pastoral Counseling* 42 (2007): 6.
- ¹⁸ Ibid. 6.
- ¹⁹ Callen, *Authentic Spirituality: Moving Beyond Mere Religion*, 17.
- ²⁰ Smith, "Conceptualizing Spirituality and Religion: Where We've Come from, Where we are, and Where we are Going," 5.
- ²¹ Peter C. Hill et al., "Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure," *Journal for the Theory of Social Behaviour* 30, no. 1 (2000): 52.
- ²² Ibid. 57.
- ²³ "Spiritual Care Near Life's End including Grief and Loss in the African American Community," accessed November 14, 2014, <http://divinity.duke.edu/initiatives-centers/iceol/resources/last-miles/papers/04>
- ²⁴ Doka, Kenneth J., Tucci, Amy S., Hospice Foundation of America., *Living with Grief: Spirituality and End-of-Life Care*, 3.
- ²⁵ Muldoon and King, "Spirituality, Health Care, and Bioethics," 330.
- ²⁶ Doka and Tucci, *Living with Grief: Spirituality and End-of-Life Care*, 1.
- ²⁷ Sulmasy, "Is Medicine a Spiritual Practice?," 1002.
- ²⁸ Brian J. Zinnbauer et al., "Religion and Spirituality: Unfuzzifying the Fuzzy," *Journal for the Scientific Study of Religion* 36 (1997): 550.
- ²⁹ Doug Oman, "Defining Religion and Spirituality," in *Handbook of the Psychology of Religion and Spirituality*, ed. R. F. Paloutzian and C. L. Park (New York: Guilford Publications, 2014), 24.
- ³⁰ Zinnbauer et al., "Religion and Spirituality: Unfuzzifying the Fuzzy," 549.
- ³¹ Ibid. 549.
- ³² Hill et al., "Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure," 51.
- ³³ Sulmasy, "Is Medicine a Spiritual Practice?," 1002.
- ³⁴ Smith, "Conceptualizing Spirituality and Religion: Where We've Come from, Where we are, and Where we are Going," 9.

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- ³⁵ Hill et al., "Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure," 56.
- ³⁶ Smith, "Conceptualizing Spirituality and Religion: Where We've Come from, Where we are, and Where we are Going," 9.
- ³⁷ Ibid. 13.
- ³⁸ Zinnbauer et al., "Religion and Spirituality: Unfuzzifying the Fuzzy," 550.
- ³⁹ Lawrence E. Cahoon, *From Modernism to Postmodernism: An Anthology Expanded*, (Malden, MA: Blackwell, 2003), 1.
- ⁴⁰ Zinnbauer et al., "Religion and Spirituality: Unfuzzifying the Fuzzy," 551.
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Chapter 5. Screening and Assessing Spirituality and Religion

5.1 The Role of Spiritual Assessments

The measuring of spirituality linked health outcomes referenced in Chapter Four are the result of qualitative and quantitative research methods. These measurements are considered important for screening patients experiencing spiritual distress and providing the appropriate intervention, as well as assisting in research.¹ Some scholars, according to Farran et al., consider spirituality as a less scientific phenomenon compared with psychological, sociological and physiological dimensions of people.² Unfortunately, if this position goes unchallenged the outcome is that this makes it possible for the importance of patient spirituality to be discounted in medical praxis. Also, because a smaller percentage of physicians identify themselves as spiritual compared to the general population³ this could further contribute to such discounting as these physicians find this particular aspect of human understanding to be less important. Furthermore, because defining spirituality is not an absolute science and given attempts to be as inclusive as possible in its definitions, modeling and assessing what may be considered ambiguous could lead to unreliable scientific outcomes. In order to make it measurable and manageable, spirituality is reduced to a rational concept but as Borneman et al. state, it then loses its “subjective and specific human experience, which makes it significant.”⁴ On the other hand, there are some who would argue that spirituality should be measured as a universal human experience in order to include the religious and non-religious alike.⁵

There is agreement among scholars that due to the multidimensionality of spirituality, any model used for its measurement and assessment must also be

multidimensional.^{6,7} Maugans asserts that the difficulties physicians have had in the past with integrating spirituality into their practice is because they operate out of a Western Cartesian construct where the mind and body are separate with impermeable bounds.⁸ Others such as Anandarajah and Sulmassy note the need to consider the patient as a complex human structure also affected by external realities.^{9,10} Correspondingly, the care following the assessment should also be multidimensional and holistic which is consistent with policies around palliative care. For the purposes of research data applied to clinical practice it is essential to measure spiritual outcomes, according to Selman et al., yet as the number of tools have increased significantly there is thus far not much guidance in terms of what tools are best used in which situations.¹¹ Some tools have been considered culturally inappropriate.^{12,13} With the requests for culturally appropriate instruments for measuring spirituality scholars note that there is not much guidance on how to do so for patients in general and those with terminal or chronic illness seeking palliative care particularly.¹⁴

In the variety of studies evaluating spirituality assessment tools and in the development of the tools themselves, definitions of spirituality and spiritual well-being have equally varied but not to the extreme. Commonly, the definitions of spirituality have focused on connectedness with the transcendent, with community, with family and with the environment while the definitions of spiritual well-being have focused on spiritual struggle along the continuum between spiritual distress and spiritual wellness. Once the assessment is completed there are some things that could possibly take place, depending on the health condition of the patient. For end-of-life situations when there are no further curative interventions available it may be best for physicians and other healthcare

providers to be present and show compassion. Sometimes when doing an assessment, Anandarajah states that an appreciation of the questions asked of the patient rather than the specific answers given triggers healing.¹⁵ This in essence is the ministry of presence that non-clergy can offer. Ministry of presence, a term found in nursing and pastoral care journals, is noted to be a response to the feeling of abandonment some terminal patients express.¹⁶ Also, as mentioned earlier, spirituality can be integrated into the treatment plan, in the form of adjuvant care, for the patient based on the information gathered during the evaluation and assessment phases, including traditional as well as non-traditional practices. Lastly, a treatment plan may be modified based on information about a patient's spiritual needs ascertained during the evaluation and assessment such as withdrawing or withholding treatment or looking to outside resources where there is stronger cultural or spiritual relevance for support.¹⁷ It is important to remember that patient centered care is the criteria for quality medical practice.

5.2 Patient-centered Care

Patient-centered care is a treatment modality that stands over and against disease centered or provider centered care and has become the focus of healthcare after a 2001 report from the Institute of Medicine. Patient-centered care as defined in that report is care that is “respectful of and responsive to patient preferences, needs and values and ensuring that patient values guide all clinical decision making.”¹⁸ It has been reported that despite the focus on patient-centered care, quality of care in the United States is worsening and lags behind other countries that are part of the Organization for Economic Co-operation and Development (OECD).¹⁹ Bergeson and Dean suggest this is because of the inconsistency of physicians in assessing patient beliefs, addressing patient concerns

and sharing treatment management options with patients. Their proposed solution to this involves a well-designed system that (1) improves patient access physicians, (2) facilitates opportunities for patients to share their concerns so that they can be included in clinical decisions, and (3) supports patient self-care, and (4) coordinates care across clinical settings.²⁰ As was argued in Chapter Two, shared decision making is essential for effective palliative care and this requires skilled communications on the part of physicians and other healthcare professionals. This can be of help most significantly for African-Americans, a demographic that scores in the top percentile of morbidity and mortality factors. Continuity of care in particular has been associated with better outcomes for patients suffering from diabetes as well as improvements in the delivery of preventive care. Improved patient scheduling through open access, also known as advanced access, is one component in recommended the system of care.²¹ This is designed to schedule visits with physicians patients want to see, those most likely who already know the patient in addition to their history. Increasing opportunities for patient participation in the care process also includes allowing time for physicians to hear and understand patient concerns. This can present a challenge in that physicians do not have unlimited time to hear and address all concerns from every patient and so prioritizing will be important.²² The reason just submitted should become null and void as of January 2016 when the Centers for Medicare and Medicaid Services (CMS) allow reimbursement for time spent by physicians with patients on advance care planning.²³ However, one should offer caution to physicians, particularly those treating African-American patients. If there is any sense that the physician is being dismissive or giving the impression that

time is a priority over the patient's care that physician may have done irreparable damage to the trust paramount in that relationship.

One way to address untrustworthy links between patient expectations and clinical decision quality mentioned earlier is through assessments. Bergeson and Dean recommend gap analysis, namely, assessing a patient's current status with what they report as ideal health. With this gap analysis a corroborated plan can be put together that the patient can signoff on and maintain.²⁴ This may work very well for patients with chronic illness, particularly those who are candidates for palliative care. Bergeson and Dean cite Moore and Wasson as advocates for the use of technology to enhance patient access and add efficiency to the visit with the physician through pre-visit work, which involves inquiring patient concerns ahead of time. Furthermore, they suggest that the use of technology can help physicians learn about patient expectations before the visit, assess the value of the care being received by the patient and barriers to self-care.²⁵ However, Epstein and Street offer a caution to the use of technology and the misunderstanding of the meaning of patient-centered care. They report that many hospitals will make superficial upgrades to their facilities like boutique hotels and implement electronic patient records and scheduling systems and still not achieve the goal of patient centered care.²⁶ Secondly these authors note that attempts to measure patient-centered care have "confounded behaviors with outcomes." In other words a patient may be satisfied with the listening skills of the physician which when measured would score well; however, if her chronic illness worsens in the process one may rightly question if the patient-centered care improved.²⁷

One thing that is generally true is that patients typically care for themselves when they are not in the hospital or in the clinic and in many cases family members assist them. To that end, patient-centered care is also family-centered care and so getting family involved earlier in the continuum of care can have tremendous benefits when the difficult end of life decisions need to be made. Linda Bell states that the goal of patient-centered care is to see the patient and family members as a single unit.²⁸ Bell, as an RN, identifies the “family presence” movement as important in recognizing the importance of family in patient decision-making. It would be well to note that there are times when the values of the patient and the values of the family are not congruent. However, those who write about and discuss the issue of family presence speak particularly about moments in the Emergency Room or Intensive Care Units where most often the medical team is preoccupied with the acute situation of the patient and often remove family members from the room e.g. when CPR is being administered or invasive procedures are being performed.^{29,30} Family presence remains an issue of debate. Baumhover and Hughes, citing a study by Timmermans, note that most healthcare professions fall into one of three categories. They are either (1) completely focused on the survival aspect of the patient during resuscitation efforts, (2) bifurcated – focused on both the survival of the patient and also the needs of the family, and (3) holistic equally concerned about all outcomes. In addition this study revealed that most inexperienced professionals fall in the survival category while most experienced professionals are bifurcated. Timmermans concluded that family presence will not be fully accepted until the attitudes and perspectives of medical professionals shift to be holistic.³¹

Some scholars have evaluated patient-centered care by the quality of the decisions made in the clinical setting.³² Specific to this point, Sepucha et al. note that physicians will at times decide what is the best course of treatment based on what makes medical sense and ignore patient preferences especially when there is multiple appropriate options. Where this began to come to light was the move by managed care organizations to control the rate of occurrence of some procedures by establishing criteria for when these procedures are appropriate to perform. When the choice between multiple treatment options has quality of life implications then it is critical to inform the patient to the fullest extent possible and allow the patient to participate in the decision making process.^{33,34} This is a key aspect of patient centeredness and as reported in *Crossing the Quality Chasm*, a report from the Institute of Medicine, links quality of care to the level of patient involvement in decision-making.³⁵ Bergeson and Dean note that efforts to address improvements in patient participation have focused primarily on physician training but suggest improving strategies to enhance the patient's role during the visit may be more successful.³⁶ How clinical decision quality is defined is also worth noting. Sepucha et al. define it as "the extent to which it reflects the considered needs, values, and expressed preferences of a well-informed patient and is thus implemented."³⁷ Discovering patient values and needs are what can be ascertained during patient interviews with some of the tools that will be discussed later in this chapter. However, patient satisfaction has long been the barometer of quality care, which Sepucha et al. challenge as an unreliable measure because it is based on patient expectations, a basis that may or may not correlate positively with quality of care.³⁸

A new paradigm in the conversation on patient-centered care is the patient-centered medical home (PCMH) concept endorsed by the American College of Physicians, the American Academy of Family Physicians and others as a way of addressing the disparities in current medical practice and optimal care. It is a team-based model, similar to the palliative care approach, with an emphasis on continuity of care, but with the following foci: a personal physician, whole person orientation, physician directed medical practice, coordinated and integrated care, quality measurement and improvement, payment reforms and enhanced access to care.³⁹ This model is designed to facilitate active participation of patients in decision-making. Martsolf et al., noting the growing emphasis on patient-centered care, also realized that very little attention had been given to resulting patient experience as opposed to patient satisfaction suggesting that satisfaction is not as useful an indicator of quality as how a patient perceived his or her experience. Therefore, they proposed to study patient experience with PCMH by focusing on interpersonal exchange, treatment goal setting, and out-of-office contact.⁴⁰ After reviewing the results of their study Martsolf et al. did not see any significant improvement in patient experience responses. They fault the results on a number of factors none of which were a flaw in the model itself. Instead they fault the research technique and protocols used, sample size, as well as some unaccounted factors such as the lag time between the implementation of presumably useful technology in a practice and when a patient realizes it in order to report a positive or negative experience. Also, they were quick to admit the possibility that there is no correlation between PCMH and patient experience outcomes. Their hypothesis and study left more questions than answers. However, one could propose that there is benefit in such an intentional structure.

The population that would most significantly benefit from such intentional efforts of coordinated care would be those mainly underserved and that historically have high morbidity and mortality rates.

It is important to note that interpersonal dynamics is a significant factor in patient-centered care and the previous discussions have shown how its importance has been viewed and measured. What will be explored later in this chapter with regards to various screening and assessment tools reviewed is both the multidimensionality of spirituality and the multidimensionality of patients. Stewart et al. factor this in their study of interpersonal processes of care. Their work was designed to explore the effect of interpersonal care on disparities in health outcomes particularly for minorities and others of low socioeconomic status.⁴¹ Interpersonal processes of care were analyzed in three different categories: communications, patient-centered decision-making, and interpersonal style. According to Nápoles et al., a review of scholarly literature concludes that patient satisfaction improves when physicians are attentive to patient needs, were supportive and assuring in their interpersonal style, and also treated patients with dignity and respect.⁴² In addition Nápoles and colleagues cite the work of several scholars who report patient dissatisfaction among minority patients when there was perceived racism in the clinical encounter.⁴³ They also note that previous research indicates a positive correlation between race/ethnic concordance with better communications and patient participation in decision-making. Therefore such evidence would support diversifying medical staff as a means of improving the quality of care.⁴⁴

One particular study that focused on African-Americans was a study by Cooper et al. in which patient-centered care in primary care settings was evaluated among African-

Americans suffering from depression.⁴⁵ The BRIDGE study by Cooper et al. was developed to compare standard collaborative care to patient-centered collaborative care with this population. The focus was patient-centeredness and cultural competence. BRIDGE is an acronym for Blacks Receiving Interventions for Depression and Gaining Empowerment. Standard collaborative care is described as “structured approaches to care based on chronic disease management principles and using depression care managers working in conjunction with a primary care physician and a mental health specialist to monitor mood and medication, coordinate care and facilitate patient engagement.”⁴⁶ Note that this alignment of primary and specialty medical professions is similar to the proposed model of palliative care. As a backdrop to their work these scholars point to other research which indicates that African-Americans with depression more often than any other ethnic group are seen and diagnosed in primary care settings, are inadequately treated with antidepressant medications and inadequately diagnosed. In addition, African-Americans are more likely to have negative attitudes toward antidepressant medications and more likely to prefer counseling and spiritual approaches while physicians are less likely to discuss depression and build rapport with them.⁴⁷ As a hypothesis for their study they surmised that patients in the patient-centered model would exhibit remission rates and a reduction in depression symptoms. It should also be noted that patients with terminal illness might at times become symptomatic with depression and even suicidal ideation.^{48,49} Therefore this focus on depression may be an appropriate link within conversations with African-American palliative care patients. This particular study’s findings are of importance because psychosocial support is an important component of

palliative care. Also, psychosocial and spiritual dimensions must be evaluated in a holistic manner for quality patient care. This will be reviewed later in this work.

What this study also supported was that clinicians were rated higher by patients in the patient-centered group. The high ratings were related to the physicians' inclusion of their patients in decision-making. This was not found in those patient-clinician relationships in the standard collaborative group. Secondly, patients in the patient-centered group had higher ratings of their depression case manager and were also more likely to adhere to their care management plan. These researchers point out that their findings are consistent with other studies that intentional focus or cultural targeting “enhances patient access and experiences.”⁵⁰

5.2.1 Human Dignity and Care

The foundations of palliative care are designed to achieve the ultimate goal of helping patients die with dignity and for the family members to participate in that journey with managed suffering.⁵¹ Dignity is the value or worth a person has simply for being human.⁵² There are varying conceptions about human dignity of which one associates its value with basic protections and minimal standards of living, which include housing, education, healthcare and a clean environment.⁵³ Where in many other countries there is an expectation that this understanding of dignity is to be supported by the state, in the United States there has been a political rub favoring individual rights. This state supported dignity is what Neomi Rao calls the dignity of welfare.⁵⁴ The leanings towards individual rights is certainly in concordance with the respect for personal autonomy within one part of the healthcare ethic paradigm but it fails to meet the communitarian ethic of providing for those who cannot substantially provide for themselves. This would

include the physically and mentally disabled as well as those people who cannot be self-sufficient because of disease progression or for other reasons. Palliative care has been defined broadly beyond the bounds of just the patient to include family, which presupposes relationships. Clifford Christians, in his work *“The Ethics of Being in a Communications Context”* cites philosopher Martin Buber where he says, “In the beginning is relation...and the relation is the cradle of actual life.”⁵⁵ While autonomy is important it is also important to recognize the patient as a person in relationship. The dignity of one affects the others with whom he or she is in relations. Rao notes that the dignity of welfare and the dignity of individual choice can conflict in the healthcare domain.⁵⁶ This is most evident with the clamoring of the chorus proposing Medicare and Medicaid reforms as well as the reactions invoked by the passage of the Patient Protection and Affordable Care Act, a government sponsored healthcare reform bill. For those that are underrepresented, particularly African-Americans, any efforts, shouldered by the government, to eliminate health or healthcare disparities has traditionally been and will likely continue to be met with resistance by those who hold fast to the belief that it is not the obligation of the government to provide healthcare. Therefore human dignity will be defined by what make sense to oneself as opposed what makes sense for the community.

A particular way to promote a more inclusive understanding of human dignity, which encompasses respecting both community and individual patient rights, is through including in shared decision-making, those people with whom the patient is in relation. Chochinov states that dignity offers a framework by which the cooperative efforts of family, patient and physician can arrive at the objectives and supportive therapies for

end-of-life care⁵⁷ and in the context of this dissertation it may be argued chronic disease management also. Promoting the human dignity of the patient begins with recognizing that the patient is not only a person but also a spiritual being enwrapped in human flesh. Chapter Four focused on spirituality and healthcare and one of the points emphasized was the importance for physicians and other medical professionals to recognize and wrestle with their own spirituality, even those who self-report as Atheists for even in their denial of a transcendent being, they are still in relationship with that which they deny. Balducci acknowledges that in order to manage human suffering, a responsibility of physicians, it is only possible through the self-awareness of spirituality for it posits them within “the mission of human rescue.”⁵⁸ In addition, he suggests that because this is a spiritual moment there are several things a physician should do in order to prepare for spiritual interventions: (1) acknowledge the privilege of being trusted with human life, (2) that one’s responsibility goes beyond disease management to personal care, (3) acknowledge the wishes of the patient thereby privileging the person over the disease, (4) be honest and truthful, respecting patient autonomy, (5) where family exists in the life of the patient, recognize them and their role in patient care.⁵⁹

When treating patients with chronic or life threatening illnesses honoring their dignity is of great importance which is one of the implied goals of patient-centered care. One of the things noted is that for patients that have undergone radical surgeries or ostomies, their sense of self can be equally radically affected.⁶⁰ It is particularly noticed among cancer patients who have had mastectomies, radical prostatectomies or other surgeries where the result is reduced functioning, body disfigurement and the feeling of worthlessness.⁶¹ For patients with terminal illness, dying with dignity or “a good death”

is important. But what was surprisingly identified as important to patients is that for some what would be considered a good death and what would also support their dignity is not being a burden to others in life as well as after death.⁶² Chochinov addresses this aspect of dignity in his dignity-conserving model of care where he posits that patient dignity is affected by three broad categories of influence: those that are illness related, those associated with the patient's spiritual and psychological resources, and environmental.⁶³ Specifically regarding the burden associated with the welfare of family and others, Chochinov aligns this with symptom distress and level of independence, which is the physical and psychological discomfort terminal patients experience and the degree of reliance on others as a result of reduced functioning respectively.⁶⁴ Chochinov associates "spiritual discomfort" or spiritual distress with the "dignity-conserving repertoire," which he defines as how patients assess and cope with their situation. It can be argued that symptom distress or the things that directly result from the illness, as Chochinov defines it, impacts the psychological and the spiritual simultaneously after which the assessing and dignity-conserving coping practices are invoked. In fact, in later writings Chochinov admits "the distinction between somatic distress and psychological or spiritual disquietude becomes less clear and increasingly entangled as death draws near."⁶⁵ This concern for the welfare of family and others is also identified in Chochinov's social dignity inventory, which examines how external influences such as family, community, and healthcare providers figure positively or negatively on patient dignity.

As evidence shows patients in advanced stages of cancer while they express desires for pain management and other symptom control, this concern is not as great as the exhibited sadness, worry and other forms of emotional distress of patients.⁶⁶ This may

in turn call for both psychological and spiritual interventions. For patients that are near death, good palliative care will acknowledge and address the existential nature of distress and provide holistic care to patients acknowledging their relationship with the world around them.

5.3 Discussion on the Importance of Screening and Assessing Spirituality and Religion

In Chapter Three the definitions of spirituality and religion along with their integration with medicine were examined. This has long been studied from the standpoint of researching common threads. Medical decision-making is not always easy for patients and studies have shown that patients often rely on their faith to either cope with their situation or in making decisions regarding treatment options.⁶⁷ This is most prevalent when the decisions are related to a terminal condition and patients are struggling with the meaning of their illness within the ontological framework of self-identity.⁶⁸ In fact, citing Maugans and Wadland's survey of patients and physicians, King and Wells report that most spiritual inquiries occur around the following life events: births, deaths, major surgeries, terminal illness and major illness.⁶⁹ Puchalski notes that in a survey of studies regarding patient preferences in physician interaction, between 41 and 94 percent of patients, who consider themselves spiritual or religious, want their physicians to engage in their spiritual needs. In addition, 50 percent of non-religious patients, according to a 1999 survey by Ehman et al., felt it was important for physicians to inquire about spiritual needs.⁷⁰ The same Ehman, cited by Puchalski, noted that the trust level of patients toward physicians correlated positively when their physician addressed their spiritual needs.

In moments when patients are facing major disease or terminal illness it is not uncommon for them to experience spiritual pain conjoined with any pain physiological or emotional in nature, which eventuates in a form of suffering.⁷¹ Since it is the goal of palliative care to alleviate patient suffering and since one of the areas physicians are mandated to examine is the spiritual needs of the patient then it is important that physicians have the means for making such assessments. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recommends that spiritual assessments be conducted but offers quite a bit of latitude as to the breadth and depth of the analysis but minimally suggest recording beliefs, practices and faith/denomination.⁷² King and Wells note that while spirituality is an important factor in patient care this is rarely reflected in patient medical records. This does not imply the conversations are not taking place but without documentation there is no way for this to be substantiated. In addition, according to a study by King and Wells where the medical records of 92 hospital patients facing end-of-life decisions were reviewed, it was found that only 6 percent of the patients had spiritual histories documented. A larger number of charts had histories recorded by psychiatrists and chaplains.⁷³ One of the things in question is who are the persons that should enter such information into patient medical histories and should this take place as an initial screening or in a more comprehensive approach. King and Wells view this as the role of the physician because the physician, in the context of palliative care, has an obligation to “counsel patients regarding such issues” and therefore if the physician is the key link in specialist referrals, e.g. chaplains, then they must own this responsibility.⁷⁴ Maugans, a physician himself, shares this opinion focusing mainly on the fundamental relationship physicians have with patients in contrast to that of social

workers, psychologists and other healthcare professionals. He endorses a model for acquiring patient spiritual histories that fosters dialogue with the patient.⁷⁵ Ambuel also agrees that while physicians should not take on the role of spiritual advisor they can be encouraging to patients and help them inquire about the fundamental spiritual questions.⁷⁶ One discipline not mentioned is that of case managers. According to the case management standards their primary role is to assess ““client health behaviors, cultural influences, and the client’s belief or value system.””⁷⁷ As was mentioned in Chapter Three, under managed care where attention to cost and profit has become a priority, spiritual care departments are being downsized. Consequently, it would be impossible for a chaplain or staff of chaplains to visit with every patient admitted to determine if that patient is in spiritual distress. It is important to also realize that the physician must honor and respect the autonomous decisions of the patient. If a patient for whatever reason decides to not participate in the assessment then that is certainly the patient’s prerogative. This stance is consistent with the informed consent doctrine and other commonly accepted ethical frameworks. Also, it should be noted that these guides and tools for assessing patient spirituality should not be used instead of the necessary conversations between the patient and attending physician.⁷⁸ For physicians who may find it difficult to integrate spirituality into their practice Anandarajah and Hight suggest the following three ways: (1) using scientific research, (2) assessing patient spirituality, and (3) therapeutic interventions.⁷⁹

The term spiritual assessment is generally used to describe the process and instruments used to ascertain the value and importance of spirituality and religion to the health and well-being of patients. There are three stages or approaches to ascertaining the

spirituality or religious needs of patients: spiritual screening, spiritual history and spiritual assessment.⁸⁰ While a spiritual history can be considered an assessment in accordance with the minimal recommendation from JCAHO, some scholars look at it as separate from the actual assessment phase. One goal of spiritual assessments is to recognize spiritual strengths in patients as well as diagnose spiritual distress.⁸¹ Spiritual distress, according to some reports positively correlates with depression, poor quality of life, rehabilitative recovery and mortality. Yet, how best to identify patients who are in spiritual distress is not clear.⁸² It is often triggered by medical illness and impending death.⁸³ Another goal of spiritual assessments is to identify how a patient's spirituality affects the types of service or care they may receive.⁸⁴ For example, Muslims may not want to take medications made of pork products and they also may not want to be examined by a person of the opposite sex. When conducting spiritual histories or other assessment methods it is important to understand that healthcare practitioners using the instruments must be comfortable and familiar with its use and the patients upon whom the instrument is used must be comfortable as well in order for conversation to be easily facilitated.⁸⁵ Hodge recommends, particularly for social workers, that the clinical practitioner conducting the assessment obtain some degree of knowledge of the patient's faith tradition before proceeding with the assessment.⁸⁶ This can be extremely important for whomever conducts the assessment, outside of a clinical chaplain, because one does not want to run the risk of initiating spiritual injury or exacerbating any spiritual distress a patient may be experiencing whether or not they are overtly exhibiting it.

Puchalski categorizes assessment approaches as either formal or informal. Formal approaches include spiritual screening, spiritual histories or spiritual assessments while

informal approaches, which Puchalski notes can be performed by anyone on the care team, key off of patient cues such as what they may be reading or wearing, what they may say implicitly or explicitly without being solicited or with the aid of an assessing instrument.⁸⁷ While Puchalski considers screenings formal, it may be appropriate to associate them with the informal category as well because when a clinician responds to unsolicited clues, verbal or nonverbal, it would appear to be a screening in the true sense of the word.

5.3.1 The Role of Spirituality Screenings

Spiritual screenings are considered initial determinations of a patient's spiritual health, specifically whether or not the patient is experiencing a spiritual crisis and is in need of further intervention.⁸⁸ It is important to note that not everyone on the care team may screen patients effectively. In a study conducted by Fitchett and Risk designed to test the use of screening protocols with patients in a medical rehabilitation facility, screenings were performed in three phases. In phase I, patient care technicians (PCT) conducted the spiritual screenings, phase II, medical residents and in phase III, psychology interns and staff psychologists. What was noted in their findings was that the PCTs and medical residents were the most inconsistent in administering the protocol. The reasons cited included lack of time, lack of understanding and high turnover of this group of staff.⁸⁹ So, while everyone can perform initial screenings as Puchalski suggests, not everyone can do it effectively due to the aforementioned constraints.

The spiritual screening protocol developed by Fitchett and Risk is a two-step model in which the first step, spiritual screening, is conducted by non-chaplain staff. The

second step, which is a more detailed assessment, is conducted by the chaplain based on the results of the spiritual screening indicating the need for a spiritual intervention.⁹⁰

5.3.2 The Role of Spirituality Histories

Spiritual histories are comprehensive interviews, similar to family histories⁹¹ and are just as important in the patient medical history as the clinical history.⁹² The moment in which a patient is willing and able to share their spiritual history is a moment where compassion can be expressed and felt. It can be a discovery of the patient's values as well as a discovery in what or in whom they find meaning⁹³ and hope amid suffering.⁹⁴ The best way to facilitate this interview is through open-ended questions because it fosters listening, and lets the patient know that the healthcare professional is interested.⁹⁵ In the spiritual screening protocol that Fitchett and Risk composed, they begin with the closed-ended question, "Is religion or spirituality important to you as you cope with your illness?" Anticipating that type of question could invoke a simple one word negative response the interviewer prepares for it with a follow-up question which simply asks, "Was there every a time when religion/spirituality was important to you?"⁹⁶ A spiritual screening is considered a type of triage⁹⁷ and as mentioned previously is meant to be conducted quickly during the initial encounter with the patient. With the spiritual history, a picture, if you will, can be painted by the patient in the mind of the healthcare professional to help humanize the person behind the medical chart. Spiritual histories can also be conducted with family members in order to get a fuller understanding of family values.⁹⁸ However, as important as spiritual histories can be for the medical staff, Borneman et al. caution that inquiring about patient spirituality can be more important in the patient/physician relationship than in hoping to complete a care plan.⁹⁹ Therefore it is

important for physicians to sense the dynamic of the patient dialogue. In citing a report by McCord et al., Borneman et al. note that patient trust with their physicians increased when spiritual histories were conducted.¹⁰⁰

A limitation of spiritual histories is that for patients who are not comfortable verbalizing their spiritual journey, this approach would not be fruitful. For them, pictorial or diagrammatic depictions may work best. Another limitation is that there may be little return on the time invested. In other words, a spiritual history may not address the present crisis.¹⁰¹

5.3.3 Spiritual History Tools

5.3.3.1 Lifemaps, Genograms, Ecomaps, Ecograms

Hodge has designed an approach to acquiring spiritual histories that involves sets of questions divided into two separate frameworks, an initial narrative framework and an interpretative anthropological framework. The first framework provides questions that assist the clinician in opening pathways for the patient to tell the story while the second framework actually provides an assessment. It does so through questions specifically designed to touch on the “six dimensions of the soul and spirit,” a framework developed by Watchman Nee. These six dimensions include affect, will and cognition for the soul and communion, conscience and intuition for the spirit.¹⁰² Therefore, for Hodge, the spiritual history process and the spiritual assessment process are integrated which in terms of terminology is confusing. Further adding to the confusion he offers pictorial or diagrammatical options to oral histories and calls them assessments rather than

alternative forms of creating histories. These alternatives are: spiritual lifemaps, spiritual genograms, spiritual ecomaps and spiritual ecograms.

Spiritual lifemaps are a pictorial view of one's spiritual journey and they set a longitudinal view from childhood to beyond death, according to Hodge. They are also considered spiritual roadmaps.¹⁰³ With spiritual lifemaps the patient actually sketches out their faith journey in sort of a timeline fashion using pictures highlighting life events or historical moments, and symbols, religious or otherwise. Hodge notes that spiritual lifemaps are client directed and because of this social workers, or others assisting the patient in completing them, may feel somewhat distanced or detached from the interaction. Furthermore, this type of assessment would not be comfortable for patients who need or prefer direct interaction.¹⁰⁴ Spiritual genograms are another diagrammatic alternative and are much like structuring a family tree. This approach not only focuses on the patient's spirituality but also looks for intergenerational patterns and linkages. Where this approach may be most helpful is with patients where family involvement and connection are central to the patient. Hodge notes that this is particularly true for Latino patients but one could also argue this also holds true for African-Americans. Latinos are considered very group oriented¹⁰⁵ and because of the history of slavery and segregation family bonds are strong among African-Americans as well.¹⁰⁶ One of the benefits of the genogram is that in identifying spiritual conflicts it may be discovered that the conflicts are family related. In this case the clinician may have better intelligence in the event a family conference is called to consult on the patient's condition. Oftentimes medical decision-making is stalled because of family conflicts. The downside to using the genogram is that it is time consuming for the clinician and the patient, and, like other

methods may not be well received by the patient.¹⁰⁷ Another approach to reviewing the importance of patient spirituality is through the use of spiritual ecomaps. Unlike spiritual histories, lifemaps and genograms that are focused on an arc of time, ecomaps focus on the patient's spiritual story at the present.¹⁰⁸ The spiritual ecomap blends the family system with the spiritual systems, those various faith communities the patient may associate with regularly with connecting lines illustrating relationships. Line thickness, dashed, and jagged indicate stronger, tenuous, and conflicted relationships respectively.¹⁰⁹ The benefit of ecomaps are that they are less time consuming compared to spiritual histories and lifemaps and as a result can address the patient's immediate spiritual needs. The limitation is the converse. Because the focus is on the patient's current spiritual realities historical foundations or causes for any forms of spiritual distress could be ignored.¹¹⁰ Lastly, ecograms combine the benefits of ecomaps and genograms looking at important spiritual elements over the course of time along with present spiritual realities.

5.3.3.2 SPIRIT Spiritual History Toolkit

The SPIRIT tool for ascertaining spiritual histories with patients is an interviewing technique developed for physicians.¹¹¹ Both Ambuel and Maugans endorse this tool for physicians. The name is a mnemonic that outlines the steps in the toolkit with "S" standing for Spiritual Belief System, "P" for Personal Spirituality, "I" for Integration and Involvement in a Spiritual Community, "R" for Ritualized Practices and Restrictions, "I" for Implications for Medical Care, and "T" for Terminal Events Planning. The first step in this tool involves identifying what faith tradition or belief system the patient associates with. As Maugans infers, even Atheists, secular humanists and Agnostics hold

some sort of belief system even if it is not one of the more prevalent or common traditions. They will more than likely engage on the subject with the physician if asked.¹¹² In reviewing the second step of the process following the letters in the mnemonic *personal spirituality* is next to be considered. Where the first step begins with a series question about one's association with a belief system, this second step begins to ask the patient how they find meaning and what about it is important to them. There may be some things a patient accepts with their spirituality or religion that gives them strength or there may be some things they reject. What is rejected could very well be a mark of spiritual injury in their past or if they consider themselves spiritual and not religious their reason for disassociating with religion may appear through what they reject. Physicians are cautioned against making assumptions at this point or generalizations. Also it is suggested that through this dialogue getting a longitudinal view from this narrative could identify any changes in belief systems.¹¹³ The primary objective of the next step, *integration and involvement with others in a spiritual community*, is to uncover any support networks the patient is associated with whether it is a church or other religious community, self-help organization such as Alcoholics Anonymous or Narcotics Anonymous, or any other social organization. For African-Americans men this could be a college fraternity or even the Masons. For African-American women it could be their college sorority or the Eastern Stars. Regardless, it is important to try to get the patient to identify someone in this network who is highly valued and supportive. The fourth step, *ritualized practices and restrictions*, looks at how the patient actualizes their spirituality or religion. They may engage in certain rituals, practices or lifestyle that bring significant meaning to them or there may be practices, rituals or other things they avoid. For

example the patient may be a vegetarian or if they are Jewish then they would only eat only kosher foods. As much literature has already determined, prayer as a form of ritualized practice, is important to many patients. The next to last step in the SPIRIT process is the review of how the patient's spirituality may affect the choices they make about their care. It is at this point that physicians can identify the barriers to healthcare that the patient's spirituality or religion may impose.

One of the more familiar religious barriers is the prohibition against the use of blood or blood products for Jehovah's Witness patients. If the patient has an advance directive, how the directive is written could be based on spiritual or religious beliefs. Therefore rather than interpreting the directive at face value it may be helpful to inquire why the patient chose or denied certain treatment options. This feeds into the final step of the process which is *terminal events planning*. It has been documented and was discussed in Chapter Four that African-Americans are least willing to put their wishes in writing and much of that is due to the mistrust of the medical system. By engaging the patient using the SPIRIT methodology a comfort level can be established and based on what was discovered earlier in the process the physician should more easily be able to direct the patient to complete an advance directive thereby minimizing if not eliminating any potential conflicts in treatment preference.

5.3.2.3 FICA Tool for Spiritual Histories

Dr. Christina Puchalski developed the FICA tool along with her colleagues, Drs. Daniel Sulmasy, Dale Matthews and Joan Teno to help physicians and other healthcare professionals understand what elements of spirituality are pertinent in a clinical environment by focusing on four domains of spiritual assessment. Those domains are

*Faith, Importance, Community, and Address.*¹¹⁴ It is believed that by using this mnemonic it will be easier for clinicians to remember what to take away from the encounter with patients. In the first domain, *Faith*, the important thing to do with this tool at this stage is to discover whether or not the patient has a belief system and if so, whether or not the patient derives meaning from it. If the patient has no belief system then it is still important to find out where they find meaning.¹¹⁵ With the second domain, *Importance*, the clinician must try to understand if and how important the spirituality is for the patient as well as whether or not it has any influence in their decision-making. Puchalski et al. note that at this point it would do well to find out from the patient who would understand their values and be able to speak on their behalf if for some reason they were not able to speak for themselves.¹¹⁶ Of course this step further supports patient autonomy in helping to determine who might best serve as surrogate decision maker for the patient, if needed. Under the domain, *Community*, the question to pose is whether or not the patient is associated with a spiritual or religious community, or any group from which the patient feels significantly supported. In the final domain, *Address* or *Action in Care*, the information gathered from the patient up to this point can now be assimilated and used to recommend a spiritual care plan e.g. chaplain referral or recommend ritualistic practices that provide strength. However, physicians or other healthcare professionals are cautioned against recommending rituals or practices that patients have not already shared are important.¹¹⁷

Puchalski admits that engaging with patients who are willing to open up and share their beliefs is in itself a sacred moment because it displays a respectable trust the patient has for the physician.¹¹⁸ Lodovico Balducci, a physician and scholar, notes that when he

visits with patients he always thanks the patient for their trust and even apologizes for anything that may interfere with the success of their physician-patient experience together.¹¹⁹

5.4 Models for Screening and Assessing Spirituality and Religion

5.4.1 HOPE Approach to Spiritual Assessment

Like the FICA tool for spiritual histories, the HOPE approach is an acronymic mnemonic where the “H” stands for *Hope*, the “O” stands for *Organized religion*, the “P” stands for *Personal spirituality and practices*, and “E” stands for *Effects on medical care and end-of-life issues*.¹²⁰ The HOPE approach to spiritual assessment is developed specifically for medical students, residents and physicians as a means of incorporating information on patient spirituality during the medical interview portion of the encounter.¹²¹ Following through with what was suggested earlier, the questions in this approach are open-ended making conversation easier to develop. One thing that makes this approach unique is that the opening lines of questions do not explicitly ask about belief systems or spirituality. Instead they focus on things in which the patient finds hope and meaning thereby creating a safe space for dialogue with those patients who are not religious, or who may be Agnostics or Atheists. This is under the category of the letter “H”. The authors have grouped the questions associated with the letters “O” and “P” together to determine if a patient’s resource(s) for hope and meaning are found in organized religion or in their personal spirituality. The final set of questions for the letter “E” investigate whether the patient has suffered from any spiritual conflict or are there

anything in their faith tradition that could have an effect on the type of care they receive.¹²²

In Chapter Four it was pointed out that Sulmasy suggested that for restoring the symbiosis between medicine and spirituality, or to facilitate the engagement of physicians with patients' spirituality, physicians should take their own religion and spirituality seriously.¹²³ Anandarajah and Hight agree and suggest that physician self-care and an awareness of their spiritual beliefs, values as well as biases will prevent them from being judgmental and remain patient centered. One way to do this is to perform a spiritual self-assessment using the HOPE questions.¹²⁴ Other advice the authors provide to facilitate discussing spirituality with patients are to establish a good relationship with the patient and have a sense for the appropriate timing for the conversation. Starting the encounter or conversation with a question on spirituality may not be the best way to begin. Anandarajah and Hight recommends that Maslov's hierarchy of needs be remembered when conducting spiritual inquiries because "routine inquiry about spiritual resources can flow naturally following discussion about other support systems and may open the door for other discussions."¹²⁵ In other words a hungry person will only become a friend after you first feed him.

5.4.2 The PLISSIT Model for Assessing Spirituality

The value of this assessment tool is drawn from the situation it was designed to address. The PLISSIT tool was designed to assist nurses and case managers in having difficult conversations with patients, particularly patients who have undergone disfigurement due to cancer surgery, reduced sexual functioning or who are even dealing with a terminal illness. It is designed for nurses because, as Dixon and Dixon state, nurses

are the first members of the healthcare team to have contact with patients and yet they often feel unprepared to discuss sexual issues with patients.¹²⁶ The PLISSIT model also serves as a reminder of the proper way to communicate with patients about psychosocial matters.¹²⁷ Like the other models explored thus far, it realizes the healthcare professional needs to be sensitive to patient values. Sometimes there is a level of discomfort on the part of the healthcare professional and perhaps even on the part of the patient. This model tries to establish a safe space for such discussions.

Unlike the other models, this model is more explicit in establishing the safe space and it is indicated in the acronym PLISSIT. The first letter, “P”, denotes giving *permission* to the patient to share but what is equally important is asking permission of the patient to explore. The other models mentioned up to this point make the assumption that just because the patient is divulging personal history that may be medical in nature, that they are also willing to have a conversation about their spirituality. As was indicated in Chapter Four, there are some patients who have indicated in studies that spirituality is not important to them. Also, as was shared by Puchalski earlier in this chapter patients will more than likely be open to speaking about their spirituality when they feel they can trust the healthcare professional and this can be a sacred moment. Therefore, not all sacred moments are open and trust should not be assumed. Also, as Anandarajah notes, if healthcare professionals are attentive to the cues provided by the patient, the patient may provide a language for discussing spirituality that is most comfortable for them, religious or secular.¹²⁸ A precaution also mentioned in Chapter Four is the risk of transference on the part of the healthcare professional, specifically, the transference of one’s belief system. A similar risk exists and is recognized by the creators of the PLISSIT model. The

author suggests that healthcare workers can transfer their discomfort with discussing sexual issues with patients thereby hindering the opportunity for dialogue. One other important difference with this tool is it serves simultaneously as an intervention as the clinician in this case is educating the patient on postoperative possibilities that may cause concern for the patient since it was primarily designed for conversations around reduced sexual functioning or bodily/image disfigurement. Therefore the remaining portions of the model, “LI” as in limited information, “SS” for specific suggestion, and “IT” – intensive therapy are not considered as appropriate and therefore will not be addressed.

5.4.3 3H and BMSEST Assessment Models

These models are unique in their analysis of people with elements worth considering in the clinical setting. The premise of these models, developed by Gowri Anandarajah, is to take into consideration the needs of the whole person from a multicultural context. This model builds on Gowri Anandarajah’s experience as a physician as well as her experience in the spiritual practices of Hinduism and Christianity and the study of Zoroastrianism, Sikhism, Jainism, mysticism, secular philosophers and the spiritual practices of Native Americans.¹²⁹ These models examine the dynamics of the mind (M), body (B), and spirit (S) based on Maslov’s hierarchy of needs not only for the patient but also the physician. It incorporates sensitivity to cultural and religious diversity. These models appear to be substantive in theory and noteworthy for medical practice.

Anandarajah uses “head”, “heart”, and “hands” as symbols in the 3H model and they serve as analogs to the cognitive, experiential, and behavioral dimensions of spirituality and asserts the universality of this association makes this model applicable to

all people regardless of culture, belief system, secular or religious.¹³⁰ Head, hand and heart are also used widely in other religious contexts thus her comfort with using them in these two models. These three constitute the spirit in the mind (M), body (B), and spirit construct (S). What is important to also note is the underlying assumption that mind, body and spirit all interact with one another. Mind, body and spirit are also affected by two external factors – the environment (E) and society (S). Within the context of healthcare and particularly for those suffering from terminal illness, patients may ponder these typical questions: Why is this happening to me? Where is God? Are my treatments congruent with my beliefs? These questions are associated with the cognitive or “head” component of the spiritual dimension in this model. The “heart” component is associated with the sense of connectedness to community, to nature and to the transcendent. It is evident when a person has been diagnosed with HIV and as a result is alone because family, friends and formerly established communities are no longer available to them or they feel disconnected from God. Another important point the author makes is that the hospital environment can have an effect on the heart dimension of patient spirituality in that if the environment is too impersonal this can contribute to a sense of disconnectedness and add to spiritual distress. The remedy in this case is what was noted earlier – being present. This requires physicians and other healthcare professionals to recognize their own humanness and vulnerabilities and therefore to be compassionate and encouraging.¹³¹ This is especially significant for patients where trust is difficult to negotiate and who have had a history of victimization. The “hands” component of the spiritual dimension is associated with spiritual practice e.g. praying, meditation, yoga, etc. As Anandarajah notes, in the area of spiritual distress, all three dimensions can be

affected simultaneously. The example she gives is the spiritual distress exhibited when a mother whose child has died struggles with meaning and purpose (head), does not feel connected to God or the transcendent (heart), and therefore is unable to pray or engage in any other spiritual practice (hands).¹³²

In the BMSEST model, also developed by Anandarajah, there is a focus on the patient-physician relationship and its corresponding dynamics involving the mind, body and spirit of each participant coupled with social and environmental influences. The significance of this comprehensive model is that it brings to the forefront of discussions that within the environment in which we all live, and given the social interactions we all have, there are common threads between the patient and the physician, which are unique to our humanness. These common threads include how patients and physicians are impacted by environmental phenomena and how the environmental phenomena also impact patient and physician. What is also common is how we impact social relations and how we are in turn impacted, and lastly, the impact transcendence has on us whether we self-identify as spiritual or secular.

While these two models do not offer step-by-step instructions for practical application in a clinical setting like some of the previous models, what they do offer is a holistic framework through which multidimensional care can be provided. According to Anandarajah, the 3-H and BMSEST models can assist physicians and other healthcare professionals to discern spiritual messaging from patients in their narratives, develop self care techniques, rediscover their own values and purpose as well as help them develop a self-awareness of their worldview and navigate cultural differences among their patients.¹³³ This may well be especially significant in offering care to African-American

patients suffering from terminal illness. Social and environmental influences significantly impact the spiritual development and trajectory of African-Americans. The converse is also true in that the spiritual development of African-Americans impacts the social and environmental constructs of life. African-American physicians and other healthcare professionals are most familiar with this integrative worldview and are therefore may be most able to connect in the 3-H intersections of patient experiences. However, this does not preclude others from being as effective.

5.5 A Proposed Model for Assessing African-American Spirituality and Religion

In a body of work developed by Lisa Lewis she analyzed the qualitative research on spirituality and wellbeing conducted over the years. The purpose of this study was to assess to what extent the various instruments that assess spirituality adequately measure spirituality among African-Americans in its practical usage in matters of health.

According to Lewis, many instruments that measure spirituality are monolithic in their approach, imposing the views or definitions of spirituality on those being evaluated.

Lewis shares that there are three spiritual attributes evident among African-Americans that impact “health beliefs and behaviors.” They are (1) faith in a transcendent force, (2) personal relationships with God, others and self, and (3) empowering transformation of and liberating consolation from adversity.¹³⁴ Based on her observations she states that these three attributes work either cooperatively or on their own in influencing health care practices or decisions.¹³⁵ Lewis concludes from her findings that of all the years of studying spirituality, they are still for the most part culturally inappropriate. She further concludes that because spirituality is less rational among the African-American community and more transcendent and ethereal, many instruments fail to capture this

unique essence.¹³⁶ It is worth reiterating that there is uniqueness in the African-American experience, channeled through African-American spirituality. Lewis' focus on the tools used in measuring the efficacy of spirituality on patient health outcomes hits the mark for research purposes. However, the tools reviewed earlier address the concerns raised by Lewis and offer a means of approaching spirituality from a holistic perspective, including the influences of relationships.

5.5.1 Family Health Histories

This section is less about the tools used for family histories and more about the process. Family history has historically been used for pedigree analysis to assess risk factors for chronic diseases for public health and preventive medicine purposes. It has been used to screen for risks of cancer, diabetes, osteoporosis, Alzheimer's disease, asthma, depression and cardiovascular disease.¹³⁷ In conferences and workshops scholars and practitioners generally agree that the best tools for ascertaining family histories should be simple to use, adaptable in many settings and inexpensive.¹³⁸ It is normally expected that the physician would be the one to ascertain family medical history from patients so as to be able to recommend targeted prevention plans. With the increase in utility of family histories there have been suggestions to raise awareness of the value of these histories through public health campaigns.¹³⁹

There have been discussions about locating family history information gathering in primary care practices especially with the increased attention and research in genetic science. Scholars remark that family histories can play a significant role in predictive genetic testing.¹⁴⁰ Barriers to obtaining family histories in the primary care practice have been identified some of which are physicians reporting lack of time because of the

current reimbursement policies at work through managed care organizations. In addition, some physicians may have a level of discomfort in their lack of skills for taking histories and then advising patients on the results.¹⁴¹ For these reasons it may make sense to look outside of the primary care physician's office for resources. Recalling the various tools for ascertaining spiritual histories, there is the potential for synergy in application particularly with the use of spiritual genograms that, like family histories, look back two or three generations and they are less time consuming than narrative versions of spiritual histories. This could be the place for expanding the services of primary care practices to include social workers. What may be more ideal would be to perhaps have social workers that also have theological backgrounds. There are some theological schools that offer joint Masters degrees in theology and social work.

5.5.2 Implementation of New Model of Spiritual Assessments for African-American Palliative Care Patients

It has been suggested that when measuring spirituality in African-Americans it should be recognized that for many, their spirituality is and has been part of their daily life¹⁴² and not just in the moment of acute illness. Spiritual Histories are an invaluable asset to have in the clinical setting. This chapter has examined several tools that can be used to ascertain spiritual histories including narrative collections, ecomaps, genograms, lifemaps, and ecograms in addition to the FICA, PLISSIT and SPIRIT tools. An approach being proposed in this chapter to be considered in providing care to African-American patients is collect spiritual histories outside of the hospital environment when possible. As mentioned previously, in January 2016, CMS will be allowing reimbursement to physicians for time spent counseling patients on advance care planning. While this is a

positive step forward in creating time and space for physicians to explore patient spirituality, the most efficient use of the time between physician and patient would involve the physician's prior knowledge of the patient's spiritual history before the encounter thereby improving the quality of the encounter. The tool that can best be used to collect that information may be the genogram because of the intergenerational profiles that can be produced. This along with family medical histories will give medical practitioners a two-dimensional profile of the patient. Professionals skilled in pastoral care can perhaps project where possible spiritual intervention may be needed depending on risk factors for chronic illness and how the patient reports using their faith as a coping mechanism. The 3H and the BMSEST models are excellent theoretical frameworks from which to design processes and protocols in which spiritual histories can be collected and spiritual assessments can be made so that applicable interventions can be recommended if necessary.

5.5.2.1 Role of Clergy and Faith Leaders

Community clergy and other faith leaders can support evidenced based medicine and make parallels with religious beliefs so that one's faith tradition does not necessarily become an impediment in receiving quality care, including palliative and end of life care.¹⁴³ In addition the personal relationship between clergy and parishioner can be an important leverage point that can be used by hospital staff, physicians, social workers and chaplains in particular, in moving patients to palliation and or hospice care. Where this effort has proven unproductive perhaps due to clinicians not feeling comfortable engaging the patient on spiritual issues as they relate to treatment options, or the spiritual care department is under-resourced due to downsizing, the clinically trained parish priest,

Jewish Rabbi, Islamic Imam or congregational pastor may be the better option. Clinical training refers to clinical pastoral education, which will be reviewed in the final chapter. In the African-American community the church has historically been the premier resource for referral if not provision of some direct social services. This has been so widely recognized that public health institutions have routinely used the church for health screenings, information dissemination and exercise centers.¹⁴⁴ One example of this form of collaboration was the Healthy Black Family project initiated by the University of Pittsburgh School of Public Health under the direction of Dr. Stephen Thomas.^{145,146}

Another example of how the pivotal office of community clergy has impacted the access to palliative and hospice care was in Pittsburgh. A local hospice and palliative care center entered a partnership with an African-American church to create an outreach program to that community. In 2010 the facility provided care for 3,300 patients of which 8 were African-American. In the first 11-months of this year 26 African-American have received services through the single contact of this pastor. This program was relatively young when this level of success unfolded and the opportunity to fully evaluate its range of implications could not be explored as the program was discontinued after institutional restructuring. However, the initial response was positive and offered compelling evidence that spirituality, when appropriately engaged may indeed provide a means to facilitate end of life decision making for this historically marginalized population. There were several proposed reasons for this success: (1) there was already an earned trust and comfort on the part of the patient in discussing spiritually related issues, (2) both patient and clergy were African-American, and (3) adequate time was allowed to explain with the patient and family member(s) the benefits of palliation and hospice care. Helping

people to reconcile questions of meaning and purpose, illness and death is best accomplished through relationships. As was noted earlier in Chapters Three and Four, African-Americans are very communal and relational; it is who they are and it is also part of their spirituality.

One area of caution is the use of clergy that do not have clinical pastoral education credits, in clinical environments. The role of the hospital chaplain is a specialized skill that disqualifies ordained clergy with generalist backgrounds from providing acute spiritual interventions. Ordained community clergy can provide a supporting role but may do more harm to patients if not properly trained. This will be discussed further in the next chapter.

5.5.2.2 Role of African-American Medical Societies

In Chapter Three the role of local African-American medical societies during the late 19th and 20th centuries was discussed. These societies played a significant part in providing support for African-American physicians during heightened segregation and other discriminatory practices in U.S. history. Their work alongside the National Medical Association and the National Hospital Association was designed to push for opening access to hospitals for African-American physicians and nurses as well as the Black Hospital Movement.¹⁴⁷ By 1914 there were fourteen local medical societies operating under the auspices of the National Medical Association. Some of these societies offered refresher courses for African-American physicians that were denied hospital privileges and medical school appointments such as the Negro Medical Association of Virginia.¹⁴⁸

Organizations that are in existence now can play a key role in supplementing what might not be easy to facilitate in the hospital or primary care practices. The T. Leroy

Jefferson Medical Society in West Palm Beach Florida has as its mission “to improve the health and wellness, access to medical care, academic and career opportunities, and the quality of life for underserved populations through the provision of healthcare, education and youth development services.” This organization partners with the FoundCare Health Center and the Florida Department of Health to make sure children are immunized and adults are educated on the effects of heart disease, diabetes, cancer and stroke. They also provide health dental health screenings and testing for HIV, blood pressured, cholesterol and glucose levels.¹⁴⁹ Another organization is the Gateway Medical Society of Pittsburgh. This organization was established in 1963 as a component of the National Medical Association to eradicate the disparities in healthcare. Their website further notes that they “realize that the general community does not always have the knowledge to recognize what is quality care, and the right course of treatment and recognize when the right care is not being delivered” and they see themselves as a bridge between the healthcare community and patients.¹⁵⁰ Like the T. Leroy Jefferson Medical Society, The Gateway Medical Society offers symposiums to the community such as their “Gateway to Wellness” series. They also provide directory services of physicians by specialty.

Several things these organizations and others like them can offer educational support and career guidance to young African-Americans seeking careers in medicine. They can assist in addressing the well-documented shortage in medical schools and thus medical practice. More on this point will be examined in the final chapter on sustaining the proposed models. Another suggestion addresses the varied opinions concerning who within healthcare practices should utilize instruments to collect spiritual histories and conduct spiritual assessments. Since these medical societies are already providing

outreach in the underserved communities, conducting front line spiritual histories should be promoted and may be collected. With ever advancing technology these histories can be collected along with family health histories, and advance directives. This information can then be made part of the patient medical history, which can be retrieved, ideally electronically, by emergency department staff and attending physicians. With the spiritual history already collected, this information can serve as a baseline for further spiritual assessment if and when the patient's health condition becomes affected by chronic disease or terminal illness leading to the appropriate spiritual interventions. What is a possibility is that a patient over a period of time may shift faith traditions. They may move from Christianity to Islam, or Buddhism to Catholicism. This possibility suggests the need to periodically assess the spiritual profile of patients which could be conducted in the primary care setting or in the emergency department.

5.5.2.3 Institutional Collaboration

Intentional outreach to the African-American community is a necessary first step in abridging the cultural mistrust African-Americans have toward wider society and white dominated institutions in particular. This could foster interdisciplinary learning opportunities. There is a correlation between the views of African-Americans towards completing advance directives, discussing end of life issues, continued life sustaining treatments and hospice utilization.¹⁵¹ According to 2011 data, 8.5 percent of the hospice patients were African-American, a number that seems surprising given the fact that at that time African-Americans were 13 percent of the total US population¹⁵² yet had and continue to have a higher mortality rate than whites.¹⁵³ Some researchers believe that this is due to the higher percentage of African-Americans who prefer to die in the hospital

due to the corresponding wish for aggressive life sustaining treatments.¹⁵⁴ In order to avoid making universal judgment on this issue, there is evidence that some African-American patients and families were not even offered hospice as an option in their care planning. In a study that evaluated 1500 deaths of which 111 were African-American, it was found that 68 percent had not used hospice and more than half of them were never informed of its availability.¹⁵⁵ As a response to this, the Initiative to Improve Palliative and End of Life Care in the African-American Community was started. From this a collaborative was formed between Memorial Sloan-Kettering Cancer Center and the East Harlem North General Hospital whereby interdisciplinary exercises took place and educational resources were brought to the African-American community.¹⁵⁶ In particular this program offered training to help African-American physicians get their certification from the American Board of Hospice and Palliative Medicine.¹⁵⁷ Also in response to the low utilization of palliative and hospice care by African-Americans, the National Hospice and Palliative Care Organization established the Task Force on Access to Hospice Care by Minorities in 1987 and the Diversity Advisory Council in 2004 mainly with the focus on the lack of cultural competence of practitioners.¹⁵⁸ In 2008 the American Medical Association (AMA) issued an apology for the role it played in promoting segregation and other discriminatory practices against “Black” physicians and for “not living up to the standards that define the noble practice of medicine.”¹⁵⁹ Since then the AMA has worked to support the recruitment of minority doctors through programs it has created. More intentional collaborations with the AMA in promoting cultural sensitivity and ameliorating implicit bias would be good next steps. More on this will be explored in the next chapter.

Another example of collaborative success is the Balm in Gilead project in Birmingham Alabama – a palliative care program of the Cooper-Green Mercy Hospital and the University of Alabama Birmingham, funded by the Robert Woods Johnson Foundation. Its success was based on engaging community partners such as churches and other volunteers to help patients and families, patients who were dying at home in substandard conditions.¹⁶⁰ Others included the PalCare program of Louisiana State University designed to integrate palliative care with aggressive HIV management. While these programs are great in their objectives, the problem lies in sustainability. Because of lack of funding, because it was a county hospital, Cooper-Green Hospital had to close its inpatient and emergency services at the end of December 2012. Also, relying on charitable foundation funding is not sustainable.

5.6 Conclusion

The purpose of this chapter was to examine a variety of tools that can be appropriately used for collecting and assessing information pertaining to the spirituality of African-American patients with chronic or terminal illness. It was mentioned earlier that scholars consider spirituality as a less scientific phenomenon compared with psychological, sociological and physiological dimensions of people, which leaves room for possible discounting in medical praxis of its efficacy in health outcomes. Spirituality also has been considered to be an ambiguous construct thereby making modeling and assessing somewhat unreliable. Recalling the holistic nature of African-American spirituality it is necessary to assess this spirituality from a holistic approach. Studies that have evaluated spirituality assessment tools acknowledge the distinction between spirituality and spiritual well-being/spiritual distress. The former focuses on

connectedness with the transcendent, community, with family and the environment while the latter focuses on spiritual struggle. Numerous studies that have evaluated patient spirituality conclude African-Americans rely on their faith more than any other ethnic group. Therefore, the focus should be on spiritual well-being, particularly, the evidence and form of spiritual wellness/wholeness and spiritual distress.

In order for this spirituality to be considered important at all requires an intentional practice in patient-centered care assessing patient values related to religion and spirituality. Being patient-centered and not treatment centered is in accordance with the dignity and respect principles that make up the standards of the medical profession and it is also what has been long been perceived to be absent by African-Americans both in the clinical setting specifically and in life in general. According to one study with minority patients, clinicians were rated higher by patients because they included the patients in the decision-making process. Patient-centeredness was intentional, which suggested intentional cultural targeting enhanced patient access and experiences. This attitude and approach makes it easier to then engage with patients on issues of values and spirituality. Spiritual histories are collected in interviews, much like family histories and this interviewing moment is an opportunity for physicians or other clinicians to show their compassion and discover patient values, hopes and meaning. A few tools for assessing patient spirituality were examined and each of them could work well in engaging African-American patients, mnemonic tools such as FICA, HOPE, PLISSIT and SPIRIT. Some literature saw social workers as the primary facilitators for some of these tools, while others saw it primarily as part of the role of the physician. For the purpose of establishing rapport and credibility it may be best if the physician was

involved in a portion of the assessment but the task of engaging the patient should be shared among all who provide care to the patient. These tools make it easy for clinicians to categorize and highlight what should be taken away from the patient encounter. However, it is the attitude and approach of the facilitator that figures most prominently. This can be accomplished when physicians are aware of and comfortable with their own spirituality or their own biases. What further helps is for physicians to be able to relate with the patient either through shared experiences or ethnicity. Because it is well documented that the number of African-Americans entering medical school is significantly less than in years past, it is important to find other ways for African-Americans and non-African-American physicians to connect with their African-American patients. The answer to that is in part through various collaborations with existing and trusted community assets such as churches, clinics, and medical societies. Building relationships before a health crisis can help eliminate distrust during a health crisis.

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Chapter 6. Sustaining the Spirituality Model for African-American Palliative Care Patients

6.1 Introduction

For many important aspects of life important things are only sustained with the proper supports and intentionality. This is no less the case in making sure the ideas put forth throughout this dissertation remain viable and become institutionalized within healthcare for a growing minority population in general and African-Americans in particular. It begins with recognizing and respecting the significant roles chaplains play in the healthcare setting and specifically with palliative care. Chaplains are too often used as bench players in the scientific world of medicine to fill in when the game is thought to be lost but they can and should play a more significant role in holistic care. But as has been remarked earlier and is clearly available in several sources, the population in the U.S. is becoming more multicultural. For those individuals in this growing demographic, many may find themselves in need of palliative care, and thus it is gravely important for them that they receive the care that also recognizes and honors their cultural values and experiential understanding. Training chaplains and clinicians in the area of spiritual and cultural competencies is greatly important in sustaining the model of care proposed. But getting beyond cultural competence and communication skills is important. Examining implicit bias and the effect it has on the encounter with patients as well as treatment recommendations is essential. This chapter will examine this concept as well as examples where it has proven to be at work.

6.2 Medical Chaplaincy and Community Support

6.2.1 The Role and Responsibilities of Chaplaincy

Palliative care is interdisciplinary in its approach. Therefore a strong cohesive team is important in delivering patient-centered care, as was argued in Chapter Five. It is suggested that teamwork is the only way to provide holistic care to the patient.¹ There are benefits beyond patient care that are predicated on the team working effectively together. Flannelly et al. in citing the work of Sommers et al. report a correlation between improved collaboration and reduced patient readmission rates.² The role and responsibility of the chaplain should not be overlooked or undervalued in this team approach. According to Norwood, the chaplain operates and navigates along the margins within the healthcare construct, among “competing structures and ideologies.”³

Throughout most of this body of work the importance and effect of spirituality in medicine broadly, and its effect on patient decision-making specifically, has been examined. Patients place emotional and spiritual support very high on their importance index. In fact it has ranked second since 1998 on the National Patient Priority Index.⁴ In 2003 the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) in their guidelines noted, “patients have a fundamental right to considerate care that safeguards their personal dignity and respects their cultural, psychosocial, and spiritual values.”⁵ In most clinical settings it is the chaplain who offers spiritual care. McClung et al. cite a study that reported higher levels of patient satisfaction, lower levels of anxiety upon discharge and shorter hospital stays when patients were visited by a chaplain.⁶ Also, as reported in the Press Ganey National Inpatient Data of 2001 there is a positive correlation between patient satisfaction and spiritual care.⁷ However, it was stated that

many benefits that chaplains bring to the clinical environment have gone undocumented.⁸ In addition, with the extensive focus on curing disease through the evolving efficacy of medicine, the spiritual aspects of the patient experience may fade into the margins leaving chaplains in the situation of having to navigate through institutional structures that revere medicine over religious practice.⁹ Various members of the healthcare team including nurses, physicians, social workers as well as chaplains can offer spiritual care.¹⁰ Even nurses, with bachelor degrees as guided by the standards of the American Association of College Nurses, should be skilled in assessing a patient's spiritual status.¹¹ Carpenter et al. offer four recommendations for nurses that are engaging spirituality in their encounter with the patient. First, the nurse must evaluate his or her own sense of spirituality. Secondly, they need to be mindful to nurture their spirituality. Third, they must be clear about the meaning and purpose of their roles. Lastly, they must enter the patient encounter with intentionality.¹² But the distinction between the services offered by the medical staff and those offered by chaplains is that the chaplain is the specialist in spiritual care and what they do is more "pastoral" in nature.¹³ Mohrmann defines this "pastoral" distinction as the ability to "hone in on the specific religiousness of the patient" without letting his or her own spirituality take over the encounter.¹⁴ Chaplains bring a different perspective about what a successful patient outcome may be based on patient spiritual values, compared to other members of the care team. While the medical team may view an unsuccessful medical intervention as a failure because a patient could not be restored to an acceptable level of functioning, the chaplain will instead view this part of journey toward peace and wholeness.¹⁵

Professional chaplaincy has changed over the past 50 years from a place where clergy who were considered marginally qualified were assigned to medical institutions to where we are today with professional standards including board certification. Although perceptions have improved greatly as this role has been professionalized, it is not yet completely where it should be. There are still some places where hospital chaplains are simply “on-call” congregational ministers.¹⁶ This model erroneously relegates the importance of patient spirituality and the value of the chaplain to the periphery. The 2005 Comprehensive Accreditation Manual for Hospitals infers that hospital chaplains should be professionally qualified “through certification or applicable licensure.”¹⁷ It should be strongly emphasized that the use of untrained community clergy to fill a role of offering spiritual and pastoral care to patients in crisis is unethical because it violates the rights of palliative care patients to receive quality physiological, psychosocial and spiritual support. Chaplains are members of two separate but interrelated professions. They are members of the orders or faith traditions in which they are ordained and they are also part of the guild of board certified chaplains. Chaplains, as ordained clergy, have an obligation to be committed to the theology and practices of their faith tradition and at the same time as they are obligated to be interfaith respecting the spirituality of the patient.¹⁸ No other profession within the healthcare system has the tension of dual professional allegiances. But chaplains have no choice but to uphold the standards of both professions. They are equipped and trained to deal with various moments of crisis, engaging patients from multiple cultures and faith traditions with compassion and sensitivity, listening for signs of spiritual distress, anger and fear.¹⁹

However, the role and importance of the hospital chaplain is viewed differently by members of various hospital departments according to an extensive study by Flannelly et al. which consisted of a national survey of hospital directors of medicine, nursing, social services and pastoral care. Several things were revealed through this survey.²⁰ As mentioned previously medical professionals as well as chaplains offer spiritual care to patients. Because of this, turf issues and role competition can ensue.²¹ The survey evaluated seven categories of the chaplain's roles: grief and death, prayer, emotional support, religious services and rituals, consultation and advocacy, community liaison/outreach, and directives and donations. Results of the survey showed that physicians rated most of these categories lower in importance for chaplains than did any of the other three disciplines. The authors believe this is because physicians view chaplains in limited traditional roles.²² What is also interesting is that while literature reports physicians view prayer as important to the patient, in this survey they rated the importance of prayer lower than any of the other disciplines. Flannelly et al. surmise this is due to scientific bias of physicians and because prayer is not viewed as scientific, physicians may see it as marginally important for patient care but not essential.²³ Social workers, like physicians, rated emotional support low. The authors believe that this is because social workers may misinterpret the connection between spiritual and emotional support and they may see patient issues as psychologically rather than spiritual related. In addition social workers in this survey did not rate advocacy and consultation high in importance for chaplains. This too is explained by the authors as possibly being due to the fact that some social workers are also case managers and patient advocates therefore believing they are equally or more qualified to fill this role.²⁴ As someone without the

responsibility of diagnosing or treating, the chaplain may at times be the neutral party needed to provide listening support for a distressed patient or family or even serve as family liaisons or advocates.²⁵ Social workers did rate community outreach/liaison as a relatively important role for chaplains presumably due to their access to communal resources. The chaplains on the other hand viewed their work around grief as central to their responsibilities especially for terminal patients. In addition they considered advocacy and consultations important considering this is part of the clergy identity developed within their religious or faith traditions.²⁶ None of the disciplines represented in this study rated dealing with organ donations and advance directives as important for chaplains although chaplains were more likely to view educating patients about advance directives within their duties.²⁷ Given the fact that chaplains express a sense of comfort in participating in advance care planning conversations suggests the opportunity for physicians to include them when meeting with patients, especially if the physician himself or herself is uncomfortable. More importantly, since it is regularly reported that spiritual care is not a revenue producing department within the hospital system, with the changes in the Medicare reimbursement protocol beginning in January 2016 permitting healthcare professionals to bill for time spent with patients in advance care planning, hopefully this moniker can become the thing of the past.

Knowing when to refer to the chaplain is important in the provision of quality patient care. McClung et al. identify three levels of interventions for nurses that may also be applicable to physicians. The first level is supporting the spiritual rituals of the patient e.g. dietary restrictions, prayers, readings, and meditation. The second level involves assisting patients in their response to positive or negative events. This could be revealed

through spiritual assessments. The last level involves recognizing spiritual distress and referring to the spiritual specialist – the chaplain.²⁸ While spiritual care has long been within the domain of physicians and nurses, accepted or not, it is the sole focus of chaplains. Spiritual care is one among many responsibilities of physicians and nurses while for chaplains it is their main responsibility.²⁹ The physician, social worker or nurse may view an emotional patient as one needing medical or psychological intervention while the chaplain would likely see it as the need for spiritual intervention. Moments like this require clarity, a type of clarity that can be achieved by a team approach. With an interdisciplinary team, efficiency in providing care is only possible when roles are clear and mutually respected. Chaplains not only provide spiritual support to patients but also are available to support the medical staff.³⁰ Mohrmann reminds us that the work of practicing medicine and offering patient care is saturated with spiritual significance not only for the patients but also for the care providers and it is important that chaplains make sure these moments of spiritual significance are “acknowledged, wrestled with, celebrated, and mourned.”³¹ Internal conflicts can arise among staff leaving employees disgruntled,³² or even suffering from moral distress, which is described as “the inability of a moral agent to act according to his or her values and perceived obligations due to internal and external constraints.”³³

Not all hospitals utilize in-house chaplains yet according to JCAHO there is the expectation that every patient will have a spiritual assessment conducted in order to understand how his or her spirituality may affect the type of care received.³⁴ Cadge et al. conducted a national survey examining the national landscape of hospitals in the United States between 1980 and 2003 to see who and how many offered chaplaincy services. In

1980, 58 percent of hospitals reported having chaplains. In 2003 that number rose nominally to 59 percent. During that twenty-three year period the percentage ranged from as low as 54 percent to as high as 64 percent.³⁵ A further review of the survey results also indicated that hospitals that were larger in size and those that were teaching hospitals were most likely to have hospital chaplaincy. One exception reported was the 540-bed Hahnemann University Hospital in Philadelphia, which in 2007 had no chaplains.³⁶ Also rural hospitals were less likely to have hospital chaplains thereby concluding the possibility that hospitals having chaplaincy services could be predicted based on geography and institutional characteristics.³⁷ Unfortunately, it is not always feasible to direct a patient in need of palliative care to a large or teaching hospital. If a patient is seeking advanced curative treatments and palliation is also prescribed there is a likelihood that the patient may have to be transported to the closest medical center with the specialists available to provide the necessary care. However, for patients with a terminal condition for whom curative measures are no longer applicable, those patients and their family deserve the right to have optimal palliative care in which all human dimensions are effectively addressed in the care plan. The survey also reports that church-operated or affiliated hospitals were more likely to have chaplains and were more likely to have discontinued or reduced their services as well.³⁸ Some hospitals that do not have staff chaplains use either volunteers or denominationally funded clergy, which JCAHO guidelines do not prohibit. Finally, what the authors of the survey conclude is that despite the JCAHO guidelines since 1980 and the subsequent revisions and amendments around spirituality and religion, these guidelines have done very little to increase the number of hospitals with chaplains.³⁹ The main thing that should be strongly

suggested is whether chaplains, whether they are volunteer, supplied by religious organizations or contracted, should be properly trained.

What cannot go unacknowledged are the expectations patients place on hospital chaplains. According to a survey of patients in intensive care, medical or surgical and rehabilitation units 50.5 percent of the patients with hospital stays of at least one week expected a chaplain to visit without explicitly requesting one and 47.3 percent expected a regular follow-up. In addition, 62.3 percent of the patients expected a visit from a chaplain at least twice a week if not daily.⁴⁰ Chaplain to patient ratios are estimated to be 1.8 full-time equivalents (FTEs) to 100 patients in most U.S. hospitals, 2.6 FTEs in religiously affiliated hospitals.⁴¹ With this level of staffing for the level of patient expectations and with the degree of spiritual care needed, it may be very difficult for optimal care to be provided. This is especially true now given the fact that over recent years patients that are hospitalized are more acutely ill and their stays are shorter.⁴²

There are some financial and structural barriers that prevent the full utilization of chaplains. Koenig recalls how in 1991 the decision was made in Georgia to discontinue the services of full-time chaplains in the state psychiatric hospitals and prisons because of a budget deficit. Some of these chaplains were later replaced with contract chaplains or volunteers.⁴³ This is still a concern where for-profit corporations are taking over hospitals.⁴⁴ Some viewed healthcare reform as another determinant of how and if chaplains would be utilized in hospitals. In a survey of 370 spiritual care department directors 27 percent reported that healthcare reform impacted them either through the downsizing of staff or the elimination of clinical pastoral education (CPE) training.⁴⁵ Koenig believes that in order to mitigate these effects chaplains should begin publishing

since the medical and healthcare fields seem to be more driven by research and the results thereof when determining what administrative decisions are made and how patients are treated.⁴⁶ While this may prove helpful there are other practical concerns regarding chaplains feeling accepted. Norwood argues that chaplains must finesse their way through the structures of hospitals balancing between embracing religion and distancing themselves from medicine.⁴⁷ Specifically, early in their profession, chaplains find themselves having to learn the language of medicine and the bureaucratic structures and organized space of the hospital. Patients are arranged by illness or illness severity, and there are rules of engagement that when comparing the hospital setting to life outside of the hospital, it is considered a different world. Norwood offers a quote from Byron Good who describes the clinical setting in this way. Good says, “The world of medicine gets built up as a distinctive world of experience, a world filled with objects that simply are not a part of our everyday world. Learning medicine is developing knowledge of this distinctive lifeworld and requires an entry into a distinctive reality system.”⁴⁸ As was commented earlier, chaplains operate from the margins. Unless a chaplain has been working in the system for some time and has developed extensive relationships there is a level of discomfort when entering a floor and integrating with staff. Unless called upon they are wandering the floors making “cold calls” and have to discern whether or not the patient welcomes their presence.⁴⁹ There is a sense of ambiguity about the role of the chaplain from the perspective of staff and even from the perspective of the chaplain.⁵⁰ The matter of socialization and acclimation is real for chaplains, a hurdle to be overcome early in the working relationship. If this is the case in general for chaplains, and given the lack of diversity among hospital staff, this could very well be an even larger hurdle for

African-American chaplains. So these environmental issues must be taken into account when diversifying the medical staff in general and the chaplaincy department in particular.

6.2.2 Education and Training of Chaplains

Some role confusion results from the lack of understanding and recognition of the extensive training required of chaplains in order to become board certified. In addition to at least three years of theological study, one must also acquire 1,600 hours of supervised clinical pastoral education. Four hundred of these hours involve studying world religions, the disease process and interpersonal skills development.⁵¹ Since 1967 the Association for Clinical Pastoral Education (ACPE) has been providing clinical pastoral education (CPE) classes in this country and currently offers over 6,500 units of training to seminarians, lay persons, clergy and health care professionals.⁵² In 2013 specialty certification in the area of palliative care began being offered as a way to help chaplains become fully accepted on the palliative care team.⁵³ CPE is considered as a juxtaposition of behavioral science and theology in an action-reflection modality.⁵⁴ This training presents chaplains with the opportunity to be with patients and their family in their suffering from sickness and death and helps the chaplains understand how to provide the appropriate spiritual support.⁵⁵ Some of the competencies a person needs to exhibit in order to be board certified are:

1. Demonstrate a sound understanding of psychological and sociological disciplines and various religious beliefs and rituals.
2. Offer pastoral care with respect for the physical, emotional and spiritual boundaries of others.
3. Respect gender, cultural, sexual, and spiritual/religious differences.

4. Demonstration and understanding of spiritual assessments for incorporating in patient treatment plans.
5. Establish and maintain professional interdisciplinary relationships.
6. Provide appropriate spiritual resources for patients and their families.
7. Support and encourage ethical decision-making.
8. Develop collaborative relationships with faith leaders and community clergy.⁵⁶

While these measured outcomes are essential for certification, including understanding and respecting cultural differences, teaching about cultures cannot replace training persons from different cultures. There is a difference between learning about a culture and being born into that culture. Jernigan notes, from his extensive experience in providing CPE training in foreign countries that the best way to provide CPE trained chaplains in foreign countries is to train people from those countries so that they can provide services.⁵⁷ While Jernigan's proposition can be narrowly interpreted to apply solely to foreign contexts this line of thinking can also be applied within the pluralistic context in the United States. The United States is home to various ethnic groups and people from a variety of cultural backgrounds. Current CPE educational standards recognize this and as mentioned earlier cultural competency is required for board certification. Jernigan states that translation from one culture to another is an art.⁵⁸ As this dissertation has shown, African-American culture is distinct as well. Suggesting the training of indigenous people to provide pastoral care in their own countries also suggests the need for training African-American chaplains to be available to provide care to African-American patients. Cultural concordance not only works in building trust between patient and physician, but can also help to build trust between patient and clergy. Creating diverse working and learning environments also creates opportunities for all to learn from each other and therefore removes assumptions of a unidirectional didactic modality. As Jernigan notes, learning about a culture that is very different from our own

can enable us to understand our own cultures even better.⁵⁹ Gender diversity would also enhance the provision of care as currently only 25 percent of hospital chaplains are female.⁶⁰ How these ideas can affect interdisciplinary care will be elaborated in the next section.

6.3 Cultural Competence in Medicine

The United States has become and continues to grow more diverse through births and with its history of immigration. With the large influx of non-English speaking immigrants, the growing pluralism has warranted attention on how patients of different cultures were being cared for. According to Chin, during the 1980s there was a paradigmatic shift from cultural sensitivity to cultural competence.⁶¹ Changes in demographics, federal legislation such as Title VI of the Civil Rights Act of 1964 have provided ample incentive for healthcare organizations to be intentional in including cultural competency in its delivery of care.⁶² Johnson, et al. identify cultural beliefs as being central to influencing health care utilization and therefore having a better understanding could improve health care outcomes and reduce disparities.⁶³ There is evidence disputing positive correlations between cultural competence and favorable health status. According to Barone, a 10-year literature review by Brach and Fraser reveal that a link between cultural competence and improved health status is inconclusive; however, these scholars opine that disparities could be reduced depending on cause – a view also supported by a 2001 Office of Minority Health report.⁶⁴ Despite varied evidence of health outcomes there has still been momentum building across academicians, policy makers, managed care organizations, and healthcare institutions to build and incorporate cultural competence to address health and healthcare disparities.⁶⁵

Cultural competence is also being explored as a tool for competitive advantage.⁶⁶ In the age of managed care and cost containment, health care institutions like other corporations are looking for ways to gain market share. As was previously mentioned, this comes sometimes at the expense of chaplains. With the increasing diversity of the population those health care organizations that are more culturally diverse in make-up as well as competence can attain an advantage.⁶⁷ Literature supports the premise that a diverse workforce correlates with improved quality of care to a diverse patient population.⁶⁸

The question then becomes, “How should cultural competence be defined?” Cultural competence is said to go beyond cultural awareness and cultural sensitivity, terms often used in the discourse of multicultural relations.⁶⁹ The U.S. Department of Health and Human services defined cultural competence as “the set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.” The California Cultural Competency Task force defined cultural competency as “affective and appropriate communications, which requires a willingness to listen to and learn from diverse populations and the provision of services and information in appropriate languages...in the context of a person’s cultural beliefs and practices.”⁷⁰ Various terms have been used to in reference to cultural competence such as cultural sensitivity, cultural responsiveness, cultural effectiveness and humility which according to Betancourt et al. indicates a lack of consensus on how to frame a strategy in addressing health disparities and the need for quality care among racial/ethnic populations.⁷¹

Eiser and Ellis state in a 2007 report that 40 percent of the population that seeks medical care are ethnic minorities with the expectation that the percentage will increase

to 50 percent by the year 2015.⁷² The situation is becoming more complex as the demographics of health care providers, namely physicians, are becoming more racially diverse. The Institute of Medicine has emphasized the need for cross-cultural training in enhancing the quality of care and eliminating disparities among racial ethnic population.⁷³ However, the number of African-Americans applying to medical schools has been on the decline. This will be discussed later in this chapter. While this emphasis from the Institute of Medicine expands the scope of attention on the need for cultural competence beyond the relation between white and non-white physicians with African-American patients, care should be taken to not dilute the urgency and seriousness of these relations specifically. The history of inequities and mistreatment of African-Americans in this country is sound reason for the advocacy of the continued responsible treatment of African-American patients by physicians who do not share this cultural heritage especially if the goal is to reduce if not eliminate healthcare disparities among this population. Literature suggests that biases, stereotyping, cultural incompetence⁷⁴, and lack of training^{75,76} on the part of medical professionals as well as mistrust⁷⁷ on the part of African-American patients and social, cultural and behavior determinants⁷⁸ are the reasons behind the high rate of health care disparities between whites and African-Americans. Betancourt reports that some literature acknowledges that the prolonged impact of racism has been linked to poor health outcomes of African-Americans.⁷⁹ It has been recorded in the literature that many minorities, especially African-Americans underutilize hospice^{80,81} and those who have used it expressed dissatisfaction with end-of-life care.⁸² While representing 13 percent of the U.S. populations, African-Americans only make up between 4 and 9 percent of hospice patients.⁸³ There is a correlate between

the views of African-Americans towards completing advance directives, discussing end of life issues, continued life sustaining treatments and hospice utilization.⁸⁴ Betancourt et al. state that understanding social context is an important component of cultural competence.⁸⁵ The history of African-American suffering was conveyed at great lengths in Chapter Three and their social context has changed only slightly today. Barone suggests that a cultural competency approach enhances the environment in which quality care can be improved and positive outcomes are more likely to occur.⁸⁶

New Jersey was the first state to require cultural competence for medical licensure.⁸⁷ In 2009, California, New York, Washington, Ohio, Arizona, Colorado, Florida, Kentucky, Georgia, and New Mexico, were debating the requirement. The state of Maryland strongly recommended it.⁸⁸ Where mandating anything is always met with some degree of opposition this issue certainly does not break from tradition. The challenge in presenting this requirement is to frame it as professional development and not in such a way that the challengers feel antagonized or feel they are being labeled as racists, says Dr. Joseph Betancourt of Harvard Medical School.⁸⁹ One underlying thought that should be deployed when dealing with cross-cultural relations or exchanges is that different does not mean deviant, according to Joseph Fins.⁹⁰ The bioethical principle of autonomy not only applies to decisions to accept or refuse treatment but also can be just as easily extrapolated to spiritual/religious preferences and should be equally respected.

6.3.1 Barriers to Cultural Competence

Recognizing the emphasis on cultural competency as a strategy for addressing racial/ethnic healthcare disparities, Betancourt et al. identified organizational, structural and clinical barriers that make cultural competency interventions difficult. Organizational

cultural competence in healthcare has been described as the ability of *systems* to provide care to patients from multiple cultures recognizing their varied values and beliefs, which includes tailoring healthcare delivery to meet social, cultural and linguistic needs.⁹¹ In the area of organizational barriers Betancourt et al. note that the degree to which health care leadership and workforce do not adequately reflect the racial/ethnic makeup of the general population affects the availability and acceptability of healthcare to minorities. For example, they report that African-Americans, Native Americans and Latinos only comprise 3 percent of the medical school faculty, 17 percent of all city and county health officers and less than 16 percent of public school faculty.⁹² Also, as was reported earlier in Chapter Four and supported here by Betancourt et al., racial concordance between medical staff, particularly physicians, and patients correlates with higher patient satisfaction and self-rated quality of care.⁹³ Reese and Beckwith identify organizational barriers to cultural competence in hospice. They note that in interviewing hospice and palliative care program directors in one southeastern state directors who were expressly not interested in cultural competency for their staff and volunteers, they intentionally hired fewer diverse volunteers which was also reflected in a less diverse patient population, showing the importance of the director in setting work climate.⁹⁴ Other noted barriers included lack of funding, ineffective community outreach, culturally insensitive policies such as required Do Not Resuscitate orders, as well as conscious or unconscious racism.⁹⁵ With regards to staffing, and particularly for African-Americans in the hospice field, the National Hospice and Palliative Care Organization invited hospices to participate in a study in which of the 207 organizations that responded it was revealed that 94 and 96 percent of the staff and volunteers respectively were white while 2 percent

of the staff, 1 percent of volunteers and 4 percent of the patients were African-American. This further confirms the lack of trust of African-Americans in the medical systems, thereby creating another barrier. When addressing disproportionate minority staffing levels at medical facilities, specifically hospice facilities, Munoz et al. report experiences shared by participants in other studies. For example, African-American clergy expressed the desire of dying patients to see a “friendly face” or someone who concords with their own race; difficult experiences with white caregivers left African-American patients feeling disrespected; complaints about service would lead to punitive outcomes and lastly the mere shame on the part of African-American caregivers of asking white authorities for assistance in caring for terminally-ill patients.⁹⁶ There seems to be a circular problem with employing African-American social workers in hospice and the utilization of hospice by African-American patients. Munoz et al., in citing MaGaughey, note African-Americans social workers are less inclined to work in hospice because of so few African-American patients and African-American patients are hesitant in using hospice because of so few African-American staff.⁹⁷ Hansen et al. note that from research conducted by LaVeist et al., African-American patients report feeling less valued by their physicians and that their illness seems less deserving of treatment.⁹⁸

There are also structural barriers that affect people of low socioeconomic status regardless of race or ethnicity; however, there are some that particularly affect minorities such as lack of interpreters in multilingual contexts, bureaucratic intake processes, and continuity of care through the specialist referral process.⁹⁹ The latter two would apply to African-Americans more than language concerns although respect for comprehension level has been mentioned in other literature. African-Americans are disproportionately

poorer than non-Hispanic whites in the United States.¹⁰⁰ African-Americans have a mortality rate that is almost twice that of whites in the United States and the morbidity rate is higher in eight of the ten leading causes of death.¹⁰¹ Studies have shown that African-Americans are at higher risk for diseases such as HIV, hypertension, cardiovascular disease, stroke and cancer many of which require care at the hands of a medical specialist. It has been reported that people with no health insurance receive less medical care and the quality of care is also diminished; this includes screenings and treatments.¹⁰² The cost of healthcare is a structural barrier for most people but especially for people with low socioeconomic status (SES). Because of cost-containment priorities of managed care, insurance companies are selective in what types of treatments or therapies they will cover. Evidence exists that for African-Americans, who are systemically exposed to social disorder and violence typically found in low-income, segregated communities there is a high risk of chronic and cognitive disease due to the associated allostatic load.¹⁰³ The allostatic load is the effect of cortisol or “wear and tear” on systems in the body due to chronic stress. A contemporary example is the stress members of the gay, lesbian and transgender population endured when society forced them to remain silent about their sexuality.¹⁰⁴ In considering the high morbidity rates of African-Americans studies have shown that certain therapies addressing chronic stress in people of low socioeconomic status have been successful in that there have been reductions in hypertension and increased glycemic control for diabetics but systemic inclusion in health care is absent and most insurance companies will not cover these therapies.¹⁰⁵ If insurance companies are unwilling to cover the cost of treatments that can ameliorate stress induced conditions, then there is no monetary incentive for healthcare

providers to treat or refer for treatment, short of good will. Which leads to clinical barriers. Reese et al. report that the results of a national survey indicate minority physicians have had difficulty referring their patients for general healthcare.¹⁰⁶

Betancourt et al. define clinical barriers as the unwillingness to accept, appreciate, understand and explore the socio-cultural differences between the clinician and the patient or patient's family during the clinical encounter. Such barriers negatively affect communication and trust.¹⁰⁷ African-American mistrust with the healthcare system is well documented.^{108,109,110} Within the area of hospice and palliative care the decision of African-American patients to use hospice is preceded by a re-evaluation of the meaning of hope, which may initially conflict with their values and spiritual beliefs.¹¹¹ The previous statement presupposes that patients are aware of hospice. If socio-cultural difference impacts effective communications then it may also speak to the reason why many African-American were never informed of the availability of hospice. A number of studies support this claim.^{112,113,114}

6.3.1.1 African-Americans in Medical School

In Chapter Three the experiential history of African-Americans seeking to become physicians was examined. It was shown that during the earlier periods in this country's history, African-Americans were denied access to medical schools but at best could only apprentice with a white physician. As a result African-Americans created their own medical schools of which Howard University was the first in 1869.¹¹⁵ During the 1960s enrollment in medical schools and the matriculation in residency programs of African-Americans increased.¹¹⁶ But even with such an emphasis, representation was far below what would have been anticipated based on population data. African-Americans

made up only 2.8 percent of the medical residents in 1978 and 6.5 percent in 1996.¹¹⁷ But unfortunately, that trend did not continue beyond the 1990s. In 2003 the American College of Physicians wrote a position paper in which they recommended increasing the number of minority physicians as a way to reduce health disparities.¹¹⁸ Yet the health disparities continue to exist even today and the number of African-Americans in medicine has not appreciated much either. According to a 2015 report from the Association of American Medical Colleges the number of African-American male applicants to medical schools has declined below 1978 numbers. In 1978 there were 1,410 applicants; in 2014 there were only 1,337 despite increases in African-American college graduates. In addition predictions estimate a shortage of physicians between 46,000 and 90,000 by 2025 amid a more diverse population.¹¹⁹ But minority physicians are not only needed to care for the minority population but also to serve as mentors to those entering or considering entering the field of medicine.¹²⁰

Challenges in recruiting minorities or underrepresented minorities (URMs) are numerous, thirty-seven barriers according to a survey conducted by the American Medical Student Association (AMSA) task force and the Student National Medical Association (SNMA).¹²¹ Some of the challenges reported were the inability of URM applicants to score at acceptable levels on the Medical College Admissions Test (MCAT), low undergraduate GPAs, communications skills, inadequate mentoring and peer support.¹²² Legislation in some cases had a negative effect on minority recruitment. For example, in the court case of *Hopwood v. Texas*, affirmative action was banned in all public universities throughout the Fifth Circuit Court in 1996. As a result where the University of Texas Southwestern Medical School before the decision interviewed forty

African-American candidates, that number dropped to four the year after.¹²³ A similar result took place in California in 1995 when the University of California board of regents banned race sensitive admissions policies for the state medical schools and in Washington State through referendum vote of the electorate.¹²⁴ Despite these legislative actions in some cases enrollment in these medical schools either increased afterwards or remained unchanged. For example, the medical school of UCLA 47.6 percent between 2000-2002, after a large drop of 40 percent in enrollment due to the Hopwood decision, the University of Texas at Dallas saw an increase from 21 African-American in 1999 or 2.4 percent of the student body to 5.4 percent in 2002 where the attendance more than doubled. On the other hand, the University of California at San Francisco saw a continued decline in enrollment of African-American students over a 5-year period after the affirmative action ban.¹²⁵ In the section below on overcoming barriers, successful strategies employed by other schools targeted at URM students will be examined.

Despite recommendations from the Institute of Medicine to diversify the student body of medical schools the number of African-American and Latinos students still lag behind the national demographic percentages. As of 2012 African-American and Latino representation in the student body was about 15 percent, which is below their combined national population percentage of 28 percent.¹²⁶

Earlier in this chapter the importance of a culturally diverse staff when providing care to what is becoming a more culturally diverse patient population was explored. Addressing the demographics of faculty in medical schools is equally important. Literature supports the argument that the inclusion of racial/ethnic physicians among a medical faculty, or in other words, underrepresented minorities in medicine (URMM),

helps medical students and other members of the faculty enhance their awareness and appreciation of cultural differences thereby improving cultural competence by sharing their knowledge and worldview as well as serving as mentors to students and residents.¹²⁷

Despite the frequent discussions on the value of recruiting and retaining underrepresented minorities as faculty in medical schools the numbers continue to indicate there remains much work to be done. Over a 20-year period from 1981-2001 the number of URMM faculty in U.S. medical schools more than tripled from 1,140 to 4060 but even this only represented 4.2 percent of total faculty nationwide. Twenty years later the percentage of minority faculty has risen to a disproportionate 7 percent of a total census of now 130,000 faculty.¹²⁸ However, even for those who are hired in these roles, the academic environment has not been a pleasant experience for a number of them. In a study by Pololi et al. of faculty from 26 U.S. medical schools they compared the experiences of minority faculty with other faculty. several disturbing findings were reported. A larger percentage of minority faculty have only reached the level of assistant professor when compared to white faculty members; minority faculty have reported being victims of harassment, discrimination, and promoted at lower rates than their white counterparts.¹²⁹

In addition to the point that there is an underrepresentation of minorities in leadership roles in medical schools also limits the opportunities for mentoring relationships. These experiences have led to problems of retention. In a separate report by Pololi et al. they evaluated the attitude of physicians that predisposes them to leaving the institution. The authors cite the work of Cropsey sharing that attrition of minority women was due to discontent with leadership, low salary, and lack of professional advancement opportunities, some of whom were African-American.¹³⁰

In looking at diversity programs in U.S. medical schools designed to achieve higher faculty diversity, Page et al. conducted a cross-sectional survey of diversity program leaders in 106 medical schools in 2010 of which 82 responded.¹³¹ When people examine the lack of diversity of the student body and of the faculty of medical schools it almost becomes a chicken and egg discussion, wondering what should come first minority students or minority faculty. Page et al. hypothesized that if the student population was diverse, 10-years later it would also be reflected in the faculty composition. The results of their study interestingly supported their hypothesis. Schools that had a higher than average number of African-American faculty had a larger than average number of African-American students 10-years earlier. What was also a supporting factor was the racial/ethnic makeup of the state population in which the medical school resided. Schools that had more than a 3 percent representation of African-American faculty had an average African-American population in that state of 22.5 percent. Schools that had more than a 4 percent representation of Latino faculty had an average population in the state of 21.1 percent.¹³² Two comments on these statistics are offered. First, a 3 and 4 percent faculty representation of any African-American and Latino population respectively is still disproportionately low based on demographic data. Second, despite the correlation of state population and racial/ethnic representation on faculty, it is beyond any school's ability to directly control the population of the state in which it resides. If in fact student diversity rates have an effect on faculty diversity, then this suggests where institutions may want to shift their recruitment emphasis and investments.

6.4 Spirituality in Medical Education

Palliative care is committed to holistic care and one of its foundational structures is spiritual care. As important as cultural competency is to the delivery of quality care, so too is the corresponding understanding of the spiritual beliefs, practices, and possible effects spirituality can have on patient decision-making, health outcomes and well being of family members. It is reported that physicians are not well trained for responding to the spiritual distress of terminally ill patients and their family members.¹³³ As was commented earlier in this chapter as well as in Chapter Four, healthcare professionals should take the opportunity to acknowledge and nurture their own spirituality. Regarding the integration of spirituality within the pedagogy of medical schools, there were only three medical schools that offered training in religion and spirituality in medicine 1993 but as of 2011 that number rose to over one hundred.¹³⁴

Physician experience in interacting with racial/ethnic patients and recognizing possible signs of spiritual distress should first be learned in medical school. This knowledge and experience is critical in the provision of quality palliative care. The argument on tailoring training for appropriate interactions with African-Americans will be covered in the section on Implicit Bias later in this chapter. Before noting the need for thorough inclusion of spirituality training in the curricula of medical schools, there have been concerns about the degree of training medical students receive in palliative care in general. A study of knowledge and attitudes toward palliative care of medical students in their final year in two schools in Germany revealed troubling results and questioned the sufficiency of medical school curricula.¹³⁵ In this study seventy-six students from Mainz and twenty-five from Göttingen participated and the results indicated most of the students

felt more confident in the subject of pain management. Only 20 percent were confident with respect to “accompaniment of severely ill or dying patients,” 43 percent were comfortable with communicating in a palliative care setting, and 27 percent expressed a level of comfort addressing psychosocial issues.¹³⁶ It should be noted that these results were ascertained at a point in time when palliative medicine was not a mandatory part of the medical curriculum. It wasn’t until 2009 that the Medical Licensure Act went into effect mandating palliative care education.¹³⁷ But while this may reflect poorly on Germany, Weber et al. note that when the “Palliative Care Examination” was given to 32 first year interns, residents and attending physicians in U.S. hospitals, only 44 percent of the interns answered correctly while 58 percent of the residents and attending physicians answered correctly.¹³⁸ These authors also refer to a study by Van Aalst-Cohen et al. that reports very few medical schools in the U.S. require formal training in palliative care but instead included the topic within existing courses. In addition the authors cite the work of Hammel et al. which noted that in 2007 only 25 percent of U.S. medical students reported being in a clinical rotation or having taken a course in end-of-life care.¹³⁹ But going back to the German program mentioned earlier, equally important is that only 17 percent of the students in Mainz and Göttingen felt confident in the area of spirituality.¹⁴⁰

There were clearly insufficiencies in the curriculum in Germany and the U.S. several years ago. But in regards to incorporating spirituality within the palliative care curricula, current research seems to indicate medical schools are still lacking in that area. Weissman et al. describe a grant program offered to sixteen qualifying medical schools over 3-years with the expressed purpose of developing three important components of palliative care education: (1) experiential opportunities for students in their final 2-years

of medical school, (2) an elective experiential opportunity in the final 2-years, and (3) a faculty development program to give faculty the foundations in providing and supervising these palliative care experiences.¹⁴¹ According to the information provided by the institutions that applied for funding their concept of experiential learning involved accompanying a hospice nurse on a home visit and attending interdisciplinary team meetings as well as observing structured clinical encounters. While this form of training is important, the authors describe it as trying to teach a person how to drive while they sit in the back seat and watch.¹⁴² What they consider to be ideal for medical school curricula are (1) supervised experiential opportunities where students perform patient palliative care assessments, perform physical exams, and develop care plans based on the assessment; (2) learning communications skills through supervised practice with feedback; (3) knowledge transfer of core palliative care principles with hospice and palliative medicine (HPM) certified faculty; (4) reflective time where the student can process his or her own emotions as a result of caring for terminal and dying patients; (5) interdisciplinary participation with hospice and palliative care teams sharing based on their own assessments and examinations of patients.¹⁴³ They further recommend moving away from observation and simulation-based instruction to more hands on clinical encounters examining real patients as they struggle physically, psychosocially and spiritually.¹⁴⁴

In a similar study of medical students at Harvard affiliated hospitals without required palliative care rotations, Smith and Schaefer surveyed eighty-eight students in their last four months of the 2012-13 academic year.¹⁴⁵ What they discovered was, 26 percent of the students never cared for a patient who died, 55 percent never delivered

significantly bad news, and 38 percent never worked with a palliative care clinician. Of the 74 percent of students who cared for a dying patient, 84 percent had one or more patient deaths that were not followed up with a debriefing and 56 percent of the students who cared for a dying patient were never debriefed.¹⁴⁶ In terms of student evaluations of training 83 percent of the eighty-eight students who responded to the survey expressed the desire for more education on caring for dying and terminally ill patients. Also almost 50 percent of the students reported caring for dying patients is depressing and 37 percent reported they would feel guilty if a patient died, and 24 percent stated they would be reticent in facing the emotional distress of family members of a dying patient.¹⁴⁷ This information supports the proposal that spirituality courses in medical school curricula should be more extensive than covering the anthropology of religion. While it is important to understand different belief systems what is more important is exploring how physicians process and reflect on their own spirituality when facing the death of others. Reflection techniques used in clinical pastoral education would be a good tool to use in debriefing medical students. With this in mind it also calls for a broader use of hospital chaplains in medical schools. However, their inclusion should be done with caution. While there is very little doubt board certified chaplains are quite skilled at what they do because of the training they go through, working among a group of published professional physicians may invoke bias on the part of medical professional. Koenig makes an excellent point that chaplains should be more involved in research with the reason being chaplains are the best people to conduct research on spirituality/religion in healthcare and Koenig cites McSherry's view that because of the focus on profits by more institutions, publications could give chaplains greater professional status.¹⁴⁸ It could

also be argued that this status would also help chaplains, or clergy gain greater acceptance in the medical setting.

Opportunities to hone one's skills in nurturing their own spirituality as well as supporting dying patients who are suffering with understanding existential meaning and hope can be addressed outside the medical school curriculum as well through various workshops or conferences. Once such program that was studied by Wasner et al. was a three and a half-day training called "Wisdom and Compassion in Care for the Dying" a training based in Buddhist practices designed to help medical professionals and volunteers recognize the different aspects of suffering and a reflection on one's own fears of death.¹⁴⁹ Those who attended the training completed evaluations afterwards. According to their findings, before attending the training, 25 percent of the attendees reported their own emotions were a problem, 31 percent reported the difficulty communicating with dying patients and their families and 27 percent reported the discomfort with dealing with difficult family members. After the training, 77 percent reported an improvement in their ability to cope with these difficulties.¹⁵⁰ Again, what this dissertation is arguing is not the need for the inclusion of religion and spirituality in medical school curricula, as there appears to already be wind in the sails of that movement. What is being argued is the need for the integration of more reflective processing in the training. This is not to create confusion about the role of physicians or to lessen the need for chaplains but to provide techniques that could lessen the degree of emotional, psychological or spiritual distress of the clinician when working with palliative care patients. An example of one school that has incorporated such reflections is Massachusetts General Hospital in Boston. Lucchetti et al. cite the study by Todres et

al. evaluating 6-years of pastoral education training that has been adapted for clinicians and the impact on patient care in the intensive care unit.¹⁵¹ This program was initiated in 1998 through the Schwartz Fellowship, the first of its kind in the country. It was setup in honor of a former patient and healthcare attorney, Kenneth B. Schwartz, who before his death stated, “we never know when, how or whom a serious illness will strike. If and when it does, each one of us wants not simply the best possible care for our body but for our whole being.”¹⁵² This fellowship programs strength comes from the involvement of CPE supervisors extensively trained in spiritual care.¹⁵³ Clinicians participate in groups of 10-12, meet for 5-months accumulating 400 hours of supervised clinical pastoral care training where the following pastoral care elements were incorporated: insight, action, experience, reflection, and integration. This training was not only for physicians but also included nurses, social workers, psychologists, clergy and seminarians.¹⁵⁴ For physicians, as well as other clinicians, the program facilitates the awareness of his or her own religion, spirituality or cultural perspectives and how these perspectives could affect patients and families, possibly inadvertently inflicting spiritual distress.¹⁵⁵ Others have described similar trainings. Fins et al. discuss reflective practice and palliative care education in medical clerkships.¹⁵⁶ Clerkships are limited apprenticeships, typically 4-12 weeks, in medical specialty fields such as surgery, medicine, pediatrics, neurology, psychiatry, etc. While these apprenticeships are designed to assist medical students, important things that are stressed during the preclinical phase such as cultural diversity, pain management, and psychosocial competency are undermined as well.¹⁵⁷ Fins et al., citing the work of Frederick Hafferty, distinguish formal, informal and hidden curricula. The formal curriculum involves coursework, labs and clinicals while the informal is

about interpersonal relations. The hidden curriculum is about the culture and norms of an institution.¹⁵⁸ This hidden curriculum is also what was alluded to earlier in regards to the chaplain's need for getting acclimated and being accepted in the different world known as the hospital. These authors also note that the impacts of these curricula can be at odds with each other such as the duties required of them through the training and their own sense of morality. To address these concerns and to foster the learning environment in which the technical and human aspects of palliative care can be integrated the Weill-Cornell Medical College created a clerkship in ethics and palliative care, which uses the reflexive techniques shared earlier. It involves relieving the student of the responsibilities of clerkship to that they can engage the humanistic dimension of practice. Also because students, as well as other clinicians may at times experience strong emotional reactions early in their encounters with dying patients this offers them time under supervision to identify their areas of discomfort.¹⁵⁹ So, the ability to reflect with peers and instructors helps them in the delivery of care to patients when the prognosis may be uncertain and hope for cure may be fading.

6.5 Overcoming Barriers

At a time when hospital administrators are looking for ways to contain costs, many hospital chaplains are concerned that the bulls-eye is on their departments.¹⁶⁰ As mentioned previously, the hospital chaplain is generally the member of the hospital staff best trained in the area of cultural competency, an area identified as crucial in mitigating health care disparities among ethnic minorities in general and African-Americans in particular. Referring to these cuts, chaplains that have experienced cuts in their departments retrospectively note that the previous tactic of cultivating positive

relationships with hospital decision-makers was not beneficial and have decided that the better strategy would have been to build interdisciplinary community support better convey the needs of patients, families and staff.¹⁶¹

6.5.1 Improving Interdisciplinary Collaborations

Earlier in this chapter the challenge of chaplaincy referrals was addressed insinuating the need in clinical settings for better interdisciplinary communications. Some of these challenges were due to lack of knowledge on when to refer, overlapping responsibilities with spirituality screenings and assessments, conflating interpretations of psychological and spiritual needs, and turf wars. The benefit of palliative care is the interdisciplinary approach where teams are configured to provide comprehensive care. Among cancer centers in the United States the extent of integration of palliative care into the traditional treatment modalities along with the scope of palliative services offered varies.¹⁶² Staffing palliative care teams has been studied, although not extensively. At the University of Texas M. D. Anderson Cancer Center they created a palliative care program of full-time members consisting of palliative care physicians, nurses, advanced practice nurses (APN), physician assistants (PA), psychiatric nurse counselors, physical and occupational therapists, a case manager, a social worker and a chaplain.¹⁶³ Over a period of 10-years they tracked the patient encounters per FTE as a way of measuring clinical burden as well as costs per patient encounter comparing against benchmark data supplied by the Center to Advance Palliative Care (CAPC). The CAPC provides staffing guidelines for institutions starting palliative care programs based on the number of hospital beds and how one should ramp up staff in accordance with anticipated consultations.

As a result of their study M.D. Anderson noticed some important similarities and divergences from these guidelines. In concordance with CAPC benchmarks, the palliative care staff at M. D. Anderson experienced a rather manageable workload in their first three years from 2000-2002 with consultations; however, over time the workload exceeded expectations and CAPC benchmarks resulting in physician turnover, which exacerbated the workload of remaining staff. In order to regain a respectable level of service for patients and a reasonable workload level for staff required aggressive recruitment of additional clinical faculty. Their program continued to see growth but several other things were required. They changed the name from palliative care to supportive care in order to facilitate referrals and decreasing distress in patients. This resulted in a 41 percent increase in referrals and early referrals by a median of 1.5 months.¹⁶⁴ At the time of launch of this palliative care program and for a time thereafter, there was resistance on the part of some personnel, which can be the case in other institution. This required a strategy to win wider support by first working with small core of advocates.

While the results of the study from M D. Anderson do not explicitly report the demographics of their palliative care staff, it is possible that this strategy that they advocate may be further improved with an aggressive recruitment strategy of clinical faculty and practitioners from underrepresented minority groups, especially African-Americans. As the incidences of chronic illness continue to increase in this country, especially among African-Americans, the population disproportionately affected, the need for palliative care consultations will also increase.

Another observation is the use of chaplains within the care team. While having a chaplain on the team is good theoretically, it is important to note that within the paradigm of palliative care spiritual support is no less important than the physical. Psychiatric, psychological and spiritual care are often placed on the margin to be called upon when needed like “bench players” rather than starters. Particularly for chaplains it is important to consider their staffing ratios to consults. In a survey conducted by Ogle in the form of semi-structured interviews with community hospital representatives at the 2007 Annual Scientific Meeting of the American Academy of Hospice and Palliative Medicine the observation was made how the presence of social workers and chaplain had little effect on the stress level reported by palliative care team members.¹⁶⁵ While this may not be true in all cases, it is quite possible that the other members of the team do not look at the chaplain as a source of support for them as well as patient and perhaps if they did, the stress level may not report as high. For this hypothesis to be proven accurate more chaplains will have to be hired in order to be able to cover the needs of the general patient population, the palliative care team(s) and palliative care patients. As Rony et al. state, effective palliative care requires effective investments and infrastructure and resource allocations, financial and human, especially if as reported earlier in this chapter, critically ill patients expected frequent follow-up visits from a chaplain.¹⁶⁶ The best solution, although difficult, to ensure the sustainability of the discipline of spiritual care in the clinical setting would be to endow the department, which would place a smaller burden on the institutions operating budget.

6.5.2 Training Beyond Cultural Competency – Implicit Bias

The history of mistreatment of African-Americans is well documented. In Chapter Three the etymology of the term race, and the etiology and epistemology of racism was examined. What developed over the four hundred plus years in the United States was not ignorance of African culture and its byproduct African-American culture, but an intentional dismissal of it and an unbridled prejudice supported in large part by policies and legislation. In the area of healthcare, a variety of scholars have researched the causes and outcomes of health and health care disparities between whites and African-Americans. Literature suggests that biases, stereotyping, cultural incompetence¹⁶⁷, and lack of training^{168,169} on the part of medical professionals and mistrust¹⁷⁰ of the health care system on the part of African-American patients along with social, cultural and behavior determinants¹⁷¹ are some of the reasons behind the high rate of health care disparities between whites and African-Americans. However, others acknowledge that racism also has been linked to poor health outcomes of African-Americans.¹⁷² A UCLA study suggests that white physicians are more likely to prescribe lifesaving HIV medications to white patients more frequently than they are to African-American patients.¹⁷³ Another report suggests that bias on the part of medical professionals continue to exist and that patient socio-demographic characteristics impact the way physicians respond and it doesn't seem to change when patient income, insurance coverage and disease severity are controlled.¹⁷⁴ Programs implemented to address the health disparities have typically focused on cultural competency and cross-cultural communication skills but the success of these programs are limited by their lack of depth in recognizing and dealing with unconscious cognitive processes.¹⁷⁵

How much of an influence the historical development of racial prejudices has had on decision-making of whites that involve African-American subjects has been recently explored the area of social cognitive psychology and is referred to as implicit and explicit bias. It is what affects the way people process information.¹⁷⁶ It is not the purpose of this dissertation to delve into the details of social psychology but there is a psychology behind this bias. Social cognition is also the area that examines intergroup relations and stereotypes.¹⁷⁷ The unconscious stereotypes Whites typically have are that Whites are intelligent, successful and educated while African-Americans are impulsive, aggressive, and lazy.¹⁷⁸ Evidence of implicit bias can be found in the legal system, law enforcement, as well as in the healthcare system. The difference between explicit and implicit racial preferences, other than the fact that explicit preferences are openly expressed, is that the two are not linked in meaning. People who express implicit biases are not the same as those who express their biases explicitly. Therefore there are some people whose values conflict with their bias due to its implicit nature.¹⁷⁹

Over the past year, ever since the death of Michael Brown by Darren Wilson, a St. Louis Metro police officer,¹⁸⁰, there has been a national cry for unbiased policing and excessive use of force. These cries have escalated with the shooting death of 9-year-old Tamir Rice¹⁸¹ by Cleveland police, the choking death of Eric Garner¹⁸² in Staten Island New York again by police, and the shooting death of Walter Scott by North Charleston police officer Michael Slager,¹⁸³ and others. These killings and others are what gave rise to the Black Lives Matter Movement. Psychologists have studied the history of stereotyping African-American males as violent criminals, according to Banks et al. these authors also remark how in another study a group of police officers were exposed to a

group of either Black faces or White faces and ask to identify who looks like a criminal. The result was that the officers identified more Black faces than White as criminals but also identified the ones who were most stereotypically black based on shape of nose, lips and skin color.¹⁸⁴ Other studies involved video game simulation with images of armed and unarmed African-American and White men with the instruction to only shoot if the suspect is armed. Results showed that images of unarmed White men were less likely to get shot than images of unarmed African-American men.¹⁸⁵ Participants in these studies also more quickly identified a handgun as a weapon after seeing the image of an African-American and other objects as non-weapons after viewing the image of a White man.¹⁸⁶

With regards to the legal system Levinson studied how mock jurors remember important facts of a case. The study results revealed that a civil plaintiff or criminal defendant's race could have an effect on the misremembering of information by jurors in racially biased ways.¹⁸⁷ He even tested to see if the manipulation of the race of the actors in the case would affect the accuracy with which mock jurors could recall events. The result was in some cases, such an altering did have an effect on factual recall.¹⁸⁸ The Implicit Association Test (IAT) has been used in cognitive research since the 1990s. It is designed to pair an attitude object with an evaluation marker. For example, the attitude object can be a racial group while the evaluative marker could be "good" or "bad" and the speed in which a person taking the test pairs the object with the marker determines the strength of an attitude.¹⁸⁹ Recognizing the seminal work of Linda Hamilton Krieger, Levinson her three major themes as it relates to social cognition and bias. They are (1) stereotyping is automatically triggered by normal cognitive processes, (2) biases and stereotyping are not linked to explicit intent, and (3) we are most often not aware of our

own cognitive processes.¹⁹⁰ These themes, this dissertation proposes, are significant in the discourse around disparities in health and healthcare, quality of care for those in need of palliation, African-American patients and a significantly disproportionate number of non-African-American physicians. With anecdotal and empirical evidence that links some behaviors by physicians to health and healthcare disparities of African-Americans, training beyond cultural competency should also be considered. The fact that we are innately unaware of our cognitive processes and that there is insufficient evidence of a link between bias and explicit intent, supports a claim that although the care delivered to African-American patients is substandard, it is not offered primarily through malice but through an unconscious prejudice. Nonetheless, the disparity in care exists. This dissertation proposes that by intentionally incorporating testing that allows medical students, residents, physicians and other clinicians to become aware of what they unconsciously project, improvement in care can be possible.

Alexander R. Green and colleagues were the first to use the IAT in the healthcare setting through a study where the test was administered to 287 internal medicine and emergency residents to predict the effect of implicit bias on the recommendation of thrombolysis for acute myocardial infarction in white and African-American patients for acute myocardial infarction.¹⁹¹ It was discovered that 67 of the participants found out what the study was about and therefore their results were excluded from the analysis. One of the IATs administered was the *Race Preference* IAT. The output scale ranged from about -.6 to 1.2. The negative range correlated with “problack” bias, “0” related to no bias, and positive numbers correlated with “prowhite” bias. The results of the test revealed the following: African-American physicians scored near zero while others had

scores in the positive “prowhite” range. Also, as the scores increased on the scale toward “prowhite” the recommendation for thrombolysis decreased indicating a significant correlation between patient race and implicit bias.¹⁹² Several other things were revealed as well. For those 67 participants who expressed foreknowledge of premise behind the tests, as their bias increased, their propensity to recommend thrombolysis to African-American patients also increased thereby supporting the reason for excluding their results from the analysis.¹⁹³ In another study that proposed recommended interventions to mitigate unintentional bias with physicians and other clinicians social cognitive psychology was the basis.¹⁹⁴ The aim of this study by Burgess et al. was to develop a framework that could be used in the clinical setting to teach medical students, and physicians how to prevent unconscious stereotypes and negative racial attitudes from affecting the patient-physician encounter.¹⁹⁵ According to Burgess et al. automatically triggered stereotypes and prejudices can be managed when people normally victimized by these attitudes and behaviors are seen more in terms of their character or other qualities than members of a social or racial class.¹⁹⁶ This was clearly the hope of Dr. Martin Luther King, Jr. when he remarked in his “I Have A Dream” speech on the mall in Washington, D.C. in 1963 “I have a dream that one day my four little children will one day live in a nation where they will not be judged by the color of their skin but by the content of their character.”¹⁹⁷ The framework the authors propose include strategies that will offer five things for the pupil: (1) improve internal abilities to reduce bias, (2) understand the psychological basis for biases, (3) enhance the confidence of the care provider in their ability to interact with people who dissimilar racially, culturally and socio-economically, (4) help manage emotions, and (5) build partnerships with

patients.¹⁹⁸ To reduce bias the authors recommend the Implicit Association Test (IAT) and develop the cognitive strategy of “individuation” which consciously directs attention toward the individual and away from their racial associations, which the authors call “categorization.” This individuation they believe will also help to understand the psychological basis of bias. In order to build confidence among care providers when interacting with dissimilar people eliminating intergroup anxiety is important and the best way to do this is through direct contact as opposed to avoidance behavior. Burgess et al. argue that many White physicians who are uncomfortable with their encounter with African-American patients will use avoidance behavior thereby limiting the amount of time spent with African-American patients compared to White patients.¹⁹⁹

Burgess et al. offer the disclaimer that their recommendations have not been proven in a healthcare setting and that because unconscious biases are habits learned over time through repetitious experiences and socialization, unlearning these “habits of the mind” will not be an easy task.²⁰⁰ Therefore patience, but forward progress, is essential. While there may be skeptics to the value of implicit measurements, study results have been rather consistent in their correlation between the degree of bias and its effect on physician decisions. Again, implicit bias measurements results do not expose overt racism but they do remind us that people with the best of intentions have an unconscious compass that may influence surprising results in their decisions in surprising ways. Finding opportunities to integrate implicit bias training into the pedagogy in medical schools along with programs and instructions on cultural competency may not only begin to eliminate disparities in health and healthcare for African-Americans but may also begin to abridge the distrust African-American patients have toward the healthcare

system in general and non-African-American clinicians specifically. The ultimate end result will be quality and equitable care.

6.6 Conclusion

The intent of this chapter was to examine the importance in sustaining a model, which recognizes and honors the uniqueness and significance of spirituality in the delivery of palliative care to African-American patients with life-limiting illness. The first concept that was examined was the role of the chaplain in relation to the emphasis on the development of modern medical science and the importance on the human body. It was noted that in this paradigm, human spirituality is often the last aspect to be attended to and as a result the chaplain operates on the margins of the healthcare team; being viewed by some as the last resort to contact when medicine has failed. This way of operating is a disloyal attempt at providing palliative care, which is designed to provide holistic care with no respect to which human dimension is given the greatest priority. Combining this marginalization with other barriers such as the slowly developing implementation of cultural competency in medical school pedagogy inhibits the optimal delivery of care to minority patients in general and African-American patients specifically. What was proposed was the use of programs aimed at the intentional recruitment of underrepresented minority students as well as underrepresented minority faculty because both of these have been linked to increased patient satisfaction and quality of care in research. What is also important is the psychological, emotional and spiritual support of clinicians. In the early stages of medical school and in the lives of many practicing physicians, handling the death of patients is difficult and can have affect the health and wellbeing of practitioners. Providing care to the members of the staff is an

important role for chaplains but given current staffing levels of spiritual care departments in hospitals it is unrealistic to attend to both patient and staff needs adequately. What this dissertation proposes is the need to incorporate more systemically, clinical pastoral education (CPE) in medical school pedagogy and ramping up the hiring of healthcare chaplains. Through significant financial investments, perhaps even through the establishment of endowments, high quality spiritual care can be made available to patients, hospital staff, and even in supervised in the reflective techniques of CPE for clinicians. Lastly, but of equal importance, is the analysis of what lurks in the background and is systemically unaddressed. This is implicit bias and the effect it has in and on interpersonal and intergroup dynamics, especially from the vantage point of White people toward African-Americans. Its explicit version is evident in overt racism but the implicit counterpart operates unconsciously even in those who adamantly denounce racial prejudices. Therefore, it is being proposed that social cognitive processing, which explores the elements of implicit and explicit bias, be integrated into the medical school curricula as well.

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Chapter 7. Conclusion

The movement of palliative care is gaining momentum in the U.S. and around the world. From its antecedent work of hospice care, a specialized form of care for the terminally ill developed in Great Britain by Cicely Saunders, palliative care was primarily a service offered by nurses and focused mainly in the area of oncology to alleviate pain and suffering for patients near the end of life. It has been argued how the deficits in-patient care for African-Americans, and their use of spirituality to cope with illness and to carry themselves through their distrust of the healthcare system must be recognized in providing quality palliative care. The positive effects in healthcare outcomes from the use of spirituality was expressed in addition to how spirituality has been a core component of palliative care in theory but still largely ignored in practice.

The rights of people to have access to quality palliative care, especially African-Americans, was examined as well as how the current inconsistent delivery of palliative care could create disadvantages for patients. The fact that there seems to be a pattern that the fewest number of hospitals with palliative care programs coincide with states with the highest population of African-Americans leaves some concern. It was also conveyed how healthcare disparities in addition to the failure of fully identifying, addressing and alleviating the suffering of patients, through the inability to provide holistic care, is a social problem.

How palliative care is received or not received among African-American patients and families is affected by the need to be aware of an African-American perspective of bioethics. In addition, African-Americans are less likely to share their medical preferences in writing. There are a number of factors considered as reasons why this is

the case such as a lack of awareness or understanding of the importance of advance care planning, mistrust in the health care system, religious and cultural beliefs. In addressing the lack of awareness or understanding some of this points to preconceived perceptions of African-American patients and or cultural insensitivity or incompetence on the part of medical professionals. Scholars also point out that African-American patients were considered less intelligent by physicians than white patients, even when controlling variables such as patient sex, age, income and education. This among other things is reason for the huge and consistent disparity in care for African-American patients.

Future developments in palliative care ethics will have to consider how to separate from a medical ethics paradigm and into an ethical identity of its own and in doing so, consider how this ethic can be applied to provide optimal care for patients suffering from diseases like Alzheimer's and dementia. Within the medical ethics paradigm patient autonomy is carefully respected and has been in response to what was considered a paternalistic disposition of physicians toward patients. However, over the course of the disease progression communications with patients challenged by these diseases becomes challenging both for the medical professional as well as for family members. Suffering for these patients takes on a different meaning, especially for Alzheimer's patients, as they are not able to share this effectively. As reported, Alzheimer and dementia patients are referred to hospice at a lesser rate than patients with other maladies. It will be of special interest to see how African-American Alzheimer and dementia patients fair given the recognized barriers to hospice care already affirmed.

Terminal sedation creates another ethical challenge both in the terminology used as well as the myriad views and opinions regarding the proper administration of opiates

and analgesics for terminal patients for whom death is either imminent, pain is refractory or both. In addition, the challenge can be exacerbated as the issue of euthanasia and physician assisted suicide gains positive acceptance in the U.S. and abroad.

Race and the construct of racial comparative frameworks have been around for hundreds of years. Along that history such comparative frameworks gave rise to a system ultimately called racism. Despite the many years of imperialistic practices in human history in which enslavement of foreigners was common, a particular European trajectory developed in which enslavement became not the bounty from military campaigns but the mechanism for human control based on skin color and the Africans were the longstanding objects. Ancient and noted theologians, philosophers and scientists developed principles, theories biblical interpretations based on flawed hypotheses masquerading as empirical evidence all to create a self-reflected superiority while relegating dark skinned people inferior, namely Africans. This gave rise to the Slave Trade, the vehicle for institutionalized slavery of Africans in America. What the Africans brought with them were the chains they did not want and the spirituality they refused to give up. This spirituality will be explored in more detail in the next chapter.

African traditional religion and practices helped the slaves forge an identity different from what slaveholders were trying to impart. The living and working conditions that slaves were subjected to were extremely unsanitary which led to a variety of illnesses and diseases. Medical care for slaves was wanting and inconsistent. Some slaveholders held the thought that a healthy slave was a good investment while others held the position that every slave was replaceable and deserving of the harshest of treatment. Because slavery was important to the southern economy efforts were made to

sustain slavery through various laws. While a disproportionately number of slaves were in the South the North was not exonerated from culpability. The difference is that slaves in the North fared only slightly better than those in the South. The Civil War marked a turning point in this country in that people were willing to fight over the issue of slavery, not because it was wrong but because it was dividing a country. Following the war the emancipated slaves found living and working conditions just as difficult afterwards as they were during slavery.

The Reconstruction Period after the Civil War launched the beginning of Jim Crow, a period in which more legislation was passed in southern states to further disenfranchise African-Americans, which lasted long after Reconstruction ended in 1877. African-Americans pushed for equality in all facets of life against the opposing tide of segregation and discrimination. Segregation and discrimination caused many African-Americans in the South to migrate north in search of better opportunities for work but those African-Americans were faced with a different form of discrimination. While the job opportunities were better than they were in the South African-Americans were still subjugated to the lowest socioeconomic status as they competed with European immigrants for housing and jobs. Still not advancing the socioeconomic disparities continued to promulgate health disparities between African-Americans and whites in morbidity and mortality rates. Because of this segregation, many hospitals would not treat African-American patients and those that offered substandard care. African-Americans were denied admission into many medical schools so they established their own. They were denied access to medical societies so they established their own. When civil rights measures forced integration and prohibited discrimination opportunities began to open for

African-Americans but not in equal measure and despite these advancing opportunities there was no amelioration of the socioeconomic or health disparities and even today African-Americans lead in most morbidity and mortality tables.

In conclusion, the history and continued challenge of oppression for African-Americans, which many would argue has undermined their human dignity. African-Americans have been and continue to be the disproportionate face of poverty throughout their history in the United States and as a result have suffered physically, emotionally and mentally. The projected outcome has been poor health and unjustified poor healthcare. David Wendell Moller, in his book “Dancing With Broken Bones,” states, “the crowning indignity of a life lived in poverty about which no one cares is a death died in poverty while the culture smiles in indifference.” As we consider all of the struggles of African-Americans across the four hundred plus years of living, working and existing as residents in this country, one cannot ignore the spiritual energy that has driven the will of this people to survive and overcome. In the next chapter we will look at the genesis of such spirituality.

Spirituality and religion have been conflated in many studies over the years and even in normal parlance the two have been used interchangeably. But spirituality is beginning to be defined over and against religion in ways that broadens it as a more inclusive domain. For many, spirituality includes religion but not the converse. It is believed by some that while not everyone is religious, all are spiritual, even atheists. As time has progressed studies have shown there are an increasing number of people self-reporting as spiritual and not religious. Some of the reasons attributed to this departure away from religion and towards spirituality are instances of spiritual injury or the

presence of unwanted and restrictive organizational structures in religion. There has been a litany of studies analyzing the effects of the integration of spirituality and religion within the context of healthcare with most evidence demonstrating positive correlations. The examination of the spirituality and religion construct, in the context of healthcare, centers around the human aspect of suffering and how this construct finds utility in amelioration efforts. Some have viewed human suffering as formative in human development. Therefore the role of spirituality and religion is to hold in tension the pain associated with the suffering and the positive development that results.

African-American spirituality while broadly defined is also very religious in its practice, resulting in a complex and holistic construct. African-American spirituality was birthed in the struggles of American slavery but has its origins in African traditional religion and its practices. Its usefulness over the centuries has been fruitful and in turn has been developed in itself. African-American spirituality found its identity in the suffering of people with hope for redemption and a way to transcend the suffering; likewise, the people found their identity in the spirituality with its focus on overcoming hardship brought on externally. In regards to palliative care it is important to recognize the significance of spirituality and religion within the care protocol. With the goal of palliative care being the alleviation of suffering it faces challenges in the African-American community in several ways. One such challenge entails the beneficial properties suffering has in the minds of some Christian African-Americans due to its alignment with the suffering of Christ and the resulting award for perseverance through suffering. The other challenge relates to the lack of access to palliative care services for some African-American patients or the lack of information about these services due to

physician bias. How patients perceive their value to physicians and how patients perceive physicians value them can create tension in the patient-physician relationship and hinder the deliver of quality care. Several studies have revealed how physicians project a bias of inferiority onto African-American patients, which has led to inadequate pain management and insufficient communications. This further confirms and validates the mistrust African-Americans have long had and continue to have toward medical professionals. In order to deliver excellent palliative care to African-American patients it will be important to find ways to understand the patient holistically e.g. physically, spiritually and socially. The social aspect involves any sociological factors that may have contributed to ontological inquiries beyond the affliction of a chronic or terminal disease. One way of doing this is through spiritual histories and other assessment models.

In this dissertation a variety of tools that can be appropriately used for collecting and assessing information pertaining to the spirituality of African-American patients with chronic or terminal illness were examined. It was mentioned earlier that scholars consider spirituality as a less scientific phenomenon compared with psychological, sociological and physiological dimensions of people, which leaves room for possible discounting in medical praxis of its efficacy in health outcomes. Spirituality also has been considered to be an ambiguous construct thereby making modeling and assessing somewhat unreliable. Recalling the holistic nature of African-American spirituality it is necessary to assess this spirituality from a holistic approach. Studies that have evaluated spirituality assessment tools acknowledge the distinction between spirituality and spiritual well-being/spiritual distress. The former focuses on connectedness with the transcendent, community, with family and the environment while the latter focuses on spiritual struggle. Numerous

studies that have evaluated patient spirituality conclude African-Americans rely on their faith more than any other ethnic group. Therefore, the focus should be on spiritual wellbeing, particularly, the evidence and form of spiritual wellness/wholeness and spiritual distress.

In order for this spirituality to be considered important at all requires an intentional practice in patient-centered care assessing patient values related to religion and spirituality. Being patient-centered and not treatment centered is in accordance with the dignity and respect principles that make up the standards of the medical profession and it is also what has been long been perceived to be absent by African-Americans both in the clinical setting specifically and in life in general. According to one study with minority patients, clinicians were rated higher by patients because they included the patients in the decision-making process. Patient-centeredness was intentional, which suggested intentional cultural targeting enhanced patient access and experiences. This attitude and approach makes it easier to then engage with patients on issues of values and spirituality. Spiritual histories are collected in interviews, much like family histories and this interviewing moment is an opportunity for physicians or other clinicians to show their compassion and discover patient values, hopes and meaning. A few tools for assessing patient spirituality were examined and each of them could work well in engaging African-American patients, mnemonic tools such as FICA, HOPE, PLISSIT and SPIRIT. Some literature saw social workers as the primary facilitators for some of these tools, while others saw it primarily as part of the role of the physician. For the purpose of establishing rapport and credibility it may be best if the physician was involved in a portion of the assessment but the task of engaging the patient should be

shared among all who provide care to the patient. These tools make it easy for clinicians to categorize and highlight what should be taken away from the patient encounter. However, it is the attitude and approach of the facilitator that figures most prominently. This can be accomplished when physicians are aware of and comfortable with their own spirituality or their own biases. What further helps is for physicians to be able to relate with the patient either through shared experiences or ethnicity. Because it is well documented that the number of African-Americans entering medical school is significantly less than in years past, it is important to find other ways for African-Americans and non-African-American physicians to connect with their African-American patients. The answer to that is in part through various collaborations with existing and trusted community assets such as churches, clinics, and medical societies. Building relationships before a health crisis can help eliminate distrust during a health crisis.

Finally, the importance in sustaining a model, which recognizes and honors the uniqueness and significance of spirituality in the delivery of palliative care to African-American patients with life-limiting illness, was examined. The first concept that was examined was the role of the chaplain in relation to the emphasis on the development of modern medical science and the importance on the human body. It was noted that in this paradigm, human spirituality is often the last aspect to be attended to and as a result the chaplain operates on the margins of the healthcare team; being viewed by some as the last resort to contact when medicine has failed. This way of operating is a disloyal attempt at providing palliative care, which is designed to provide holistic care with no respect to which human dimension is given the greatest priority. Combining this marginalization with other barriers such as the slowly developing implementation of cultural competency

in medical school pedagogy inhibits the optimal delivery of care to minority patients in general and African-American patients specifically. What was proposed was the use of programs aimed at the intentional recruitment of underrepresented minority students as well as underrepresented minority faculty because both of these have been linked to increased patient satisfaction and quality of care in research. What is also important is the psychological, emotional and spiritual support of clinicians. In the early stages of medical school and in the lives of many practicing physicians, handling the death of patients is difficult and can have affect the health and wellbeing of practitioners. Providing care to the members of the staff is an important role for chaplains but given current staffing levels of spiritual care departments in hospitals it is unrealistic to attend to both patient and staff needs adequately. What this dissertation proposes is the need to incorporate more systemically, clinical pastoral education (CPE) in medical school pedagogy and ramping up the hiring of healthcare chaplains. Through significant financial investments, perhaps even through the establishment of endowments, high quality spiritual care can be made available to patients, hospital staff, and even in supervised in the reflective techniques of CPE for clinicians. Lastly, but of equal importance, is the analysis of what lurks in the background and is systemically unaddressed. This is implicit bias and the effect it has in and on interpersonal and intergroup dynamics, especially from the vantage point of White people toward African-Americans. Its explicit version is evident in overt racism but the implicit counterpart operates unconsciously even in those who adamantly denounce racial prejudices. Therefore, it is being proposed that social cognitive processing, which explores the elements of implicit and explicit bias, be integrated into the medical school curricula as well.

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